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Deciding to Forego Life-Sustaining Treatment

Ethical, Medical, and Legal Issues in Treatment Decisions

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

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A Report on the
Ethical, Medical,
and Legal Issues in
Treatment Decisions

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United States
President's Commission for the Study of
Ethical Problems in Medicine and
Biomedical and Behavioral Research

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President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research

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cutions of health care professionals for killing patients are almost nonexistent.[67] The major reason must be that such killings are rare; when they do occur, some may go undetected, and those that are detected are seldom prosecuted, perhaps because of the difficulty in obtaining a conviction.[68]

Nevertheless, the threat of prosecution provides an appropriate protection against abuse. While "there is precious little precedent" one way or the other, as the Supreme Judicial Court of Massachusetts has observed, "what there is suggests that the doctor will be protected if he acts on a good faith judgment that is not grievously unreasonable by medical standards."[69] Since neither wrongful shortening of life by physicians nor

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[67] Although physicians have been defendents in murder cases in this country and abroad under a variety of circumstances, until recently only two American physicians have ever been tried for "mercy killing"; both were acquitted by juries. In 1973, Dr. Vincent Montemarano was indicted in the death of a 59-year-old comatose cancer patient, charged with causing his death by injection of potassium chloride. He successfully denied any role in the killing and argued that there were numerous other possible causes of death. People v. Montemarano, Indictment No. 37707, Nassau County Court, N.Y. (1974).

The other case also involved a cancer patient. In 1950, Dr. Hermann Sander was charged with the murder of Mrs. Abbie Barroto, having recorded in her chart, "patient was given 10cc. of air intravenously four times. Expired within ten minutes after this was started." Again, acquittal came after the jury found that the cause of death could not be established with sufficient certainty. O. Ruth Russell, Freedom to Die: Moral and Legal Aspects of Euthanasia, Human Sciences Press, New York (1975) at 100-03; Daniel C. Maguire, Death by Choice, Doubleday & Co., New York (1974) at 20-26.

[68] Cases involving physicians have turned on *factual* innocence. When nonphysicians have been charged with "mercy killings" of close relatives, they have usually relied upon *legal* innocence, asserting defenses of temporary insanity and similar exculpatory claims. Veatch, *supra* note 41, at 80. In a number of cases juries have recognized these defenses and acquitted such defendants. *See, e.g.*, the case of Lester Zygmaniak, acquitted on the basis of temporary insanity in shotgun murder done at the request of his brother, paralyzed in an accident four days previously. Paige Mitchell, Act of Love: The Killing of George Zygmaniak, Alfred A. Knopf, New York (1976); R. Johnston, *'Mercy Killer' Acquitted on Insanity Pleas*, N.Y. Times, Nov. 6, 1973, at A-1. There have been a few convictions; in some of these, however, sentences have been greatly mitigated. *See, Texan Given Probation in Brother's Mercy Death*, N. Y. Times, March 5, 1982, at A-12; note 66 *supra*.

[69] *In re* Spring, 405 N.E.2d 115, 121 (Mass. 1980). The court also noted that "it is reported that apparently no prosecutor has proceeded to trial in a case where a physician chose to terminate life-preserving treatment or omit emergency treatment in a hopeless case." *Id. But see* note 71 *infra*.

failure to give appropriate medical treatment for fear of the criminal law appears to be prevalent, society seems well served by retaining its criminal prohibition on killing, as interpreted and applied by reasonable members of the community in the form of prosecutors, judges, and jurors.[70] Of course, in an era when medical and community standards are being reevaluated in light of changes in biomedical and sociocultural circumstances, some uncertainty about "reasonable medical standards" is inevitable.[71] If the considerations and procedures

[70] Martin v. Commonwealth, 184 Va. 1009, 37 S.E.2d 43 (1946); Turner v. State, 119 Tenn. 663, 108 S.W. 1139 (1907); Helen Silving, *Euthanasia: A Study in Comparative Criminal Law*, 103 U. Pa. L. Rev. 350 (1954); Norman St. John-Stevas, Life, Death and the Law, World Publishing Co., New York (1961) at 262. Many proposals have been made either explicitly to authorize direct killing of certain patients, *see* Humphry, *supra* note 49, at 6, 94, or to provide physicians with a "mercy defense" to homicide charges. *See, e.g.*, James Rachels, *Euthanasia*, in Tom Regan, ed., Matters of Life and Death, Temple Univ. Press, Philadelphia (1980) at 28, 63-66; Frederick Stenn, *A Plea for Voluntary Euthanasia* (Letter), 303 New Eng. J. Med. 891 (1980). It would be difficult to demonstrate that either reform is likely to reduce the harm of nontreatment without increasing the harm of too rapid death precisely because there is so little evidence of serious systematic abuse at present. *See* David Brand, *Right to Die Groups Seek Another Right to Aid in Suicide*, Wall St. J., Sept. 4, 1980, at 1.

The possibilities for civil and criminal liability are enhanced if any of the above conditions are absent—especially if a health care professional were to use means that characteristically are associated with criminal homicide rather than merely cooperating with the patient's refusal of treatment. *See* Donald G. Collester, Jr., *Death, Dying and the Law: A Prosecutorial View of the Quinlan Case*, 30 Rutgers L. Rev. 304, 310-11 (1977); John B. Nesbitt, *Terminating Life Support of Mentally Retarded, Critically Ill Patients: The Prosecutor's Perspective*, 3 J. Legal Med. 245 (1982); James Vorenberg, *Decent Restraint on Prosecutorial Power*, 94 Harv. L. Rev. 1521, 1558 (1981).

A Canadian study commission recommended ensuring prosecutorial caution by adding a provision to the Canadian criminal code that would allow charges of aiding or counseling suicide to be brought against a physician only upon personal written authorization of the Attorney General. Law Reform Commission of Canada, Euthanasia, Aiding Suicide and Cessation of Treatment, Minister of Supply and Services, Ottawa (1982) at 68-69.

[71] The possibility of criminal liability for deliberate omissions is demonstrated by the recent indictment of two physicians on charges of murder and conspiracy to commit murder in the case of Clarence H. Herbert, a 55-year-old comatose patient at Kaiser-Permanente Hospital in Harbor City, California. Ted Rohrlich, *2 Doctors Face Murder Charges in Patient's Death*, L. A. Times, Aug. 19, 1982, at A-1; Jonathan Kirsch, *A Death at Kaiser Hospital: How Medical Politics Turned a Clash between Two Doctors and a Nurse into a Case for the District Attorney*, 7 California 79 (Nov. 1982). The indictments were dismissed after a preliminary hearing. Magistrate's Findings, California

suggested in this Report are taken into account, however, there appears to be no basis for concern that the law provides an inadequate or unsuitable framework within which practitioners, patients, and others can make decisions about life-sustaining care.[72]

Suicide, or "self-killing," could be an issue with a dying patient either through an act or an omission of action. The common law treated suicide as a crime and punished both those who performed (or attempted) it and those who aided them.[73] Though suicide is no longer punished as a felony, a suicide attempt—regardless of a person's motive—is a basis for active intervention by public officers and for deprivation of liberty (through involuntary psychiatric observation and treatment).[74] Furthermore, a number of states continue to consider the assisting of suicide a crime.[75]

Since this Report is concerned with the ethics of foregoing life-sustaining treatment, the Commission did not investigate the effects any remaining legal rules on suicide have on

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v. Barber and Nejdl, No. A 025586 (Los Angeles Mun. Ct., Cal., March 9, 1983). *See also* David Margolick, *Hospital Is Investigated on Life Support Policy*, N.Y. TIMES, June 20, 1982, at A-34; Loy Wiley, *Liability for Death: Nine Nurses' Legal Ordeals*, 11 NURSING81 34 (Sept. 1981).

[72] In cases dealing with incompetent patients who have never stated their preferences about the continuation or cessation of a particular treatment, there is considerably more uncertainty about the latitude of permissible actions that physicians may take, and some courts have asserted that treatment may be withheld only after having obtained judicial permission. *See* pp. 154-57 *infra*. *See also* 65 Ops. Cal. Att'y Gen. 417 (1982), *reprinted in* Appendix I, pp. 536-45 *infra*. (Even courts are said to lack power to authorize withdrawal of treatment from incompetent patients.)

[73] Under the English common law, from which a good deal of American law derives, suicide—literally, "self-killing"—was considered a crime. The punishment for suicide was ignominious burial and forfeiture of the individual's property to the Crown. T. Plucknett, A CONCISE HISTORY OF THE COMMON LAW, Little, Brown, Boston (1948) at 420. Attempted suicide was a lesser offense. Glanville Williams, THE SANCTITY OF LIFE AND THE CRIMINAL LAW, Alfred A. Knopf, New York (1957) at 273-85. Suicide was decriminalized in England in 1961, Suicide Act of 1961, 9 & 10 Eliz. 2, Ch. 60 §1 (1961), and is no longer a crime in any American jurisdiction. Norman L. Cantor, *A Patient's Decision to Decline Life-Saving Medical Treatment: Bodily Integrity versus the Preservation of Life*, 26 RUTGERS L. REV. 228, 246 (1973). However, attempted suicide remains a crime in a few American jurisdictions, although the last reported prosecution was in 1961. *See* State v. Willis, 255 N.C. 473, 121 S.E.2d 854 (1961).

[74] David F. Greenburg, *Involuntary Psychiatric Commitments to Prevent Suicide*, 49 N.Y.U. L. REV. 227 (1974).

[75] Humphry, *supra* note 49, at 94; Richard S. Scott, *"Rational Suicide" For the Terminally Ill?*, 9 LEGAL ASPECTS MED. PRACTICE 1, 6 n.6 (Nov. 1981) (lists 23 states where assisting suicide remains a crime, although the rules governing liability as an accessory or conspirator differ).

decisions by dying patients to deliberately try to kill themselves. The continuing public policy of condemning suicide has, however, played a role in judicial consideration of cases involving a foregoing of treatment. Although in the 1960s some courts relied on the analogy to suicide when they refused to permit treatment to be foregone,[76] in recent years judges have consistently distinguished between suicide and the refusal of treatment by, or on behalf of, terminally ill patients.[77] Some courts did so by treating the earlier cases as examples of incompetent or unreasonable refusals of "life-saving" treatments (refusals that can legitimately be prevented), as distinct from competent refusals of treatments that are at best "life-prolonging" but not curative. Furthermore, in cases in which treatment refusal has been found to be acceptable, courts have held that death resulted from a "natural cause"—the patient's illness—which means that the patient's death was not considered to result from suicide, since it was neither self-inflicted nor "caused" by health professionals who honored the patient's decision to refuse treatment.[78] The Commission has not found any instances in which criminal or civil liability has been imposed upon health professionals or others (such as

[76] *See, e.g.*, Application of the President and Directors of Georgetown College Inc., 331 F.2d 1000, 1009 (1964).

[77] "There is a real and in this case determinative distinction between the unlawful taking of the life of another and the ending of artificial lifesupport systems as a matter of self-determination." *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 670, *cert. denied*, 429 U.S. 922 (1976).

[78] In the case of the competent adult's refusing medical treatment such an act does not necessarily constitute suicide since (1) in refusing treatment the patient may not have the specific intent to die, and (2) even if he did, to the extent that the cause of death was from natural causes the patient did not set the death producing agent in motion with the intent of causing his own death. Furthermore, the underlying state interest in this area lies in the prevention of irrational self-destruction. What we consider here is a competent, rational decision to refuse treatment when death is inevitable and the treatment offers no hope of cure or preservation of life. There is no connection between the conduct here in issue and any State concern to prevent suicide.

Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 426 n.11 (1977) (citations omitted); *see also* Satz v. Perlmutter, 362 So.2d 160 (Fla. App. 1978), *aff'd* 379 So.2d 359 (Fla. 1980).

Since a patient has a right to refuse life-saving treatment, that right necessarily entails a right on the part of others to effectuate the patient's refusal, and no prosecution could occur for aiding an act that is not itself a crime. "The constitutional protection extends to third parties whose action is necessary to effectuate the exercise of that right." *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 670, *cert. denied*, 429 U.S. 922 (1976). The difficulties of relying on attributions of causation to explain the distinction are discussed at pp. 68-70 *infra*.

family members) for acquiescing in a patient's refusal of life-sustaining treatment.[79]

Civil law. Rather than punishing people for behavior that offends social norms, civil law strives both to prevent violations of those norms and, when that is not possible, to require the violator to compensate those who have been harmed by the violation. Although the branch of civil law known as the law of torts attempts to protect human life, autonomy, and well-being, it does not bar health care professionals from exposing patients to risk; if it did, many valuable health care services would not be provided.[80] Rather, practitioners may administer treatments (and diagnostic procedures) that subject patients to "reasonable" risks to life and limb, but damages must be paid if death or other harm ensues from practitioners' conduct that violates the standards of reasonable behavior established by the profession or that contravenes any agreement that the professional and the client had about their relationship and mutual duties.[81]

Civil courts also exercise the powers of *parens patriae* to protect individuals who cannot adequately defend their own interests.[82] In this role, courts are the final authority as to who needs such protection, who should provide it (such as a guardian appointed for an incompetent patient), and what standards should be applied.[83]

When a court is faced with a "human being of adult years and sound mind," then its function is to protect that person's "right to determine what shall be done with his body."[84] Determining the exact meaning of this credo, its application in each particular case, and the legitmacy of various encroachments on it has led to (and probably will continue to generate)

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[79] *See* Robert S. Morison, *Alternatives to Striving Too Officiously*, in Franz J. Ingelfinger *et al.*, eds., CONTROVERSY IN INTERNAL MEDICINE II, W.B. Saunders, Philadelphia (1974) at 119.

[80] The social benefit that accrues from pursuit of an activity is a legitimate consideration in determining the reasonableness of the activity. RESTATEMENT (SECOND) OF TORTS, American Law Institute Publishers, St. Paul, Minn. (1965) at § 292(a).

[81] The risk-taking activities of engineers, accountants, plumbers, and lawyers are all judged by the standards of their respective professions. Prosser, *supra* note 65, at 161-62; James M. Smith, *The Nurses and Orders Not to Resuscitate* (Commentary), 7 HASTINGS CTR. REP. 27 (Aug. 1977); Jay Alexander Gold, *Wiser than the Laws?: The Legal Accountability of the Medical Profession*, 7 AM. J. L. & MED. 145 (1981).

[82] Prince v. Massachusetts, 321 U.S. 158 (1944); AMERICAN JURISPRUDENCE, Lawyers Co-Operative Pub. Co., Rochester, N.Y. (2nd ed. 1971) at *Parent and Child* § 1, 9, 10.

[83] For a discussion of guardianship and of the probate function of the courts, see pp. 121-31 *infra*.

[84] Schloendorff v. Society of New York Hosp., 211 N.Y. 125, 129, 105 N.E. 92, 93 (1914).

numerous court cases. These cases have been brought both by patients who seek to compel health care professionals and institutions to take certain steps (for example, to forego treatment) and by professionals and institutions that seek to declare the rights of the parties, particularly when there is doubt about the capacity or authority of a patient to forego treatment.

A number of state legislatures have adopted statutes that would permit dying patients in advance of incompetence to authorize physicians to withhold life-saving treatment without involving the courts, thus specifying the presumptions under which decisions about incompetent patients are to be made. The first and best-known of these "natural death" acts, which was adopted by California in 1976, expressly states that withholding treatment is not to be construed as homicide or suicide.[85] These judicial opinions and legislative declarations are the logical corollary of the doctrine of informed consent, which holds that patients are entitled to choose the treatment option, if any, they wish to pursue. The test of the depth of this commitment comes when the choice may result in or hasten death.[86] Courts faced with these situations have increasingly taken the view that "the value of life...is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice."[87]

Governmental administration and regulation. A wide range of government activities are aimed at structuring the society so as to advance the general welfare or the welfare of especially disadvantaged persons. Unlike criminal law, these provisions are not principally meant to punish individual wrongdoers. And, unlike the civil law, they do not redress or oversee individual cases. Rather, reductions or expansions of benefits are used to regulate behavior. Thus, for example, a state license to practice medicine can be revoked if a physician demonstrates a pattern of substandard practice, even if there has been no finding in an individual case of criminal wrongdoing or civil liability. Often the power of these laws and regulations are most effectively used to shape institutions and practices and to prevent misuse and error. This is especially true when the withdrawal of benefit because of a particular wrongdoing would actually punish innocent parties more substantially than it would harm those responsible for the wrong.

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[85] Cal. Health & Safety Code § 7192(a)(Deering Supp. 1982), *reprinted in* Appendix D, pp. 324-29 *infra*.

[86] A. M. Capron, *Right to Refuse Medical Care*, in 4 ENCYCLOPEDIA OF BIOETHICS, The Free Press, New York (1978) at 1498.

[87] Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 426 (1977).

Administrative and regulatory law has been used in health care mainly to expand opportunities for care and to improve its quality.[88] Very little attention has been given to providing programmatic incentives for good decisionmaking practices or disincentives against inadequate ones.

[88] *See* SECURING ACCESS TO HEALTH CARE, *supra* note 47, at 119-82.

The Elements of Good Decisionmaking

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Patients whose medical conditions require treatment to sustain life usually want the treatment and benefit from it. Sometimes, however, a treatment is so undesirable in itself or the life it sustains is so brief and burdened that a patient—or a surrogate acting on the patient's behalf—decides that it would be better to forego the treatment. This chapter considers how life-sustaining treatment decisions should be made and the ethical and legal constraints on such decisions that might be warranted.

Shared Decisionmaking

In considering the issue of informed consent,[1] the Commission recommended that patient and provider collaborate in a continuing process intended to make decisions that will advance the patient's interests both in health (and well-being generally) and in self-determination.[2] The Commission argued that decisions about the treatments that best promote a patient's health and well-being must be based on the particular patient's values and goals; no uniform, objective determination can be adequate—whether defined by society or by health professionals.

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[1] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, MAKING HEALTH CARE DECISIONS, U.S. Government Printing Office, Washington (1982). Arguments for the recommendations given here and further elaborations of the consequences can be found in that Report and its two volumes of Appendices.

[2] Self-determination, sometimes called "autonomy," involves a person forming, revising over time, and pursuing his or her own particular plan of life. *See* John Rawls, *Rational and Full Autonomy*, 77 J. PHIL. 524 (1980).

Respect for the self-determination of competent patients is of special importance in decisions to forego life-sustaining treatment because different people will have markedly different needs and concerns during the final period of their lives; living a little longer will be of distinctly different value to them. Decisions about life-sustaining treatment, which commonly affect more than one goal of a patient (for example, prolongation of life and relief of suffering) create special tensions. Nonetheless, a process of collaborating and sharing information and responsibility between care givers and patients generally results in mutually satisfactory decisions.[3] Even when it does not, the primacy of a patient's interests in self-determination and in honoring the patient's own view of well-being warrant leaving with the patient the final authority to decide.

Although competent patients thus have the legal and ethical authority to forego some or all care,[4] this does not mean that patients may insist on particular treatments. The care available from health care professionals is generally limited to what is consistent with role-related professional standards and conscientiously held personal beliefs. A health care professional has an obligation to allow a patient to choose from among medically acceptable treatment options (whether provided by the professional or by appropriate colleagues to whom the patient is referred) or to reject all options. No one, however, has an obligation to provide interventions that would, in his or her judgment, be countertherapeutic.

In most circumstances, patients are presumed to be capable of making decisions about their own care. When a patient's capability to make final decisions is seriously limited, he or she needs to be protected against the adverse consequences of a flawed choice. Yet any mechanism that offers such protection also risks abuse: the individual's ability to direct his or her own life might be frustrated in an unwarranted manner. In its report on informed consent, the Commission recommended that a surrogate—typically a close relative or friend—be named when a patient lacks the capacity to make particular medical decisions.[5] As much as possible, surrogates

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[3] *See generally* Ned H. Cassem, *Procedural Protocol When Illness is Judged Irreversible*, in Edward Rubenstein and Daniel D. Federman, eds., SCIENTIFIC AMERICAN MEDICINE, Scientific American, Inc., New York (1980) at 13-V-1; Bernard Lo and Albert Jonsen, *Clinical Decisions to Limit Treatment*, 98 ANNALS INT. MED. 764 (1982).

[4] A. M. Capron, *Right to Refuse Medical Care*, in 4 ENCYCLOPEDIA OF BIOETHICS, The Free Press, New York (1978) at 1498; Norman L. Cantor, *A Patient's Decision to Refuse Life-Saving Medical Treatment: Bodily Integrity versus the Preservation of Life*, 26 RUTGERS L. REV. 228 (1973).

[5] MAKING HEALTH CARE DECISIONS, *supra* note 1, at 181-88. The considerations that enter into a decision to turn to a surrogate

and providers of care should then make decisions as the particular patient would have.

Decisionmaking Capacity. Determining whether a patient has sufficient decisionmaking capacity to make choices about health care treatment is based on three considerations: the abilities of the patient, the requirements of the task at hand, and the consequences to the patient that are likely to flow from the decision. The individual must have sufficiently stable and developed personal values and goals, an ability to communicate and understand information adequately, and an ability to reason and deliberate sufficiently well about the choices.[6]

Just as for medical treatment generally, deciding about a patient's decisionmaking abilities when the patient is facing a complex and confusing situation or making a decision of great consequence requires both the wise judgment of others and procedures that regularly yield morally and legally acceptable decisions. The Commission has found no reason for decisions about life-sustaining therapy to be considered differently from other treatment decisions. A decision to forego such treatment is awesome because it hastens death, but that does not change the elements of decisionmaking capacity and need not require greater abilities on the part of a patient. Decisions about the length of life are not necessarily more demanding of a patient's capabilities than other important decisions. And decisions that might shorten life are not always regarded by patients as difficult ones: a patient who even with treatment has a very short time to live may find a few additional hours rather unimportant, especially if the person has had a chance to take leave of loved ones and is reconciled to his or her situation.

Thus, determining whether or not a patient lacks the capacity to make a decision to forego life-sustaining treatment will rest on generally applicable principles for making assessments of decisional incapacity in medical care. Of course, when a patient who could have a substantial time to live rejects life-sustaining treatment, close inquiry into the components of that person's decisionmaking capacity is warranted in order to protect the individual from harms that arise from incapacities that themselves diminish the value of self-determination.[7]

Voluntariness. A patient's choice is binding when it is selected freely—that is, when the patient can decide in accord with his or her own values and goals.[8] Selection among options

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(including the steps that are appropriate to overcome the causes of a patient's incapacity) and the procedures and standards for surrogate decisionmaking are also treated in pp. 121-36 *infra*.

[6] MAKING HEALTH CARE DECISIONS, *supra* note 1, at 169-75.

[7] *Id.* at 44-51.

[8] *Id.* at 63-68.

must not be so influenced by others that free choice is precluded, and relevant treatment options must therefore be made available to the patient. Furthermore, the patient must be situated so as to feel that he or she is expected to have the final word in the treatment decision. Of course, patients do not make decisions in isolation from others. Complex networks of relationships and roles make the responses of other parties very important to patients and to their decisionmaking.

One of the things that patients rightly expect from professionals, and that professionals usually expect to provide, is advice rather than neutral information about treatment options and their risks and benefits. However, the way advice is provided can vary substantially. Individual personality styles, both of the professional and of the patient, range from authoritarian through nondirective to dependent.

Drawing the line between influence that is legitimate and that which is not is difficult both conceptually and in practice.[9] Often distinctions are suggested between "coercion," "fraud," "duress," "deceit," and "manipulation"—all of which are said to be unacceptable—and "influence," "persuasion," and "advice"—which are expected, and perhaps even desired. The use of these labels conveys a judgment as to whether an action would interfere with voluntary choice or not, but the categories are too poorly defined to provide a generally accepted basis for judging the difficult cases. It is important, therefore, to develop a fuller understanding of acceptable conduct in the interaction of health care professionals and others with patients.

Professional care givers and a patient's close friends and family[10] have two major roles to play when someone faces a decision about life-sustaining treatment. First, their actions, words, and presence help shape the patient's assessment of the best course of treatment. Second, their ability and willingness to carry out various decisions often define the range of options available to the patient.[11]

Shaping the patient's deliberations. How information is communicated and continuing care is provided can forcefully induce a patient to make certain choices. In many medical care

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[9] *Id.*

[10] "Family" is defined broadly in this Report to include closest relatives and intimate friends, since under some circumstances, particularly when immediate kin are absent, those most concerned for and knowledgeable about the patient may not be actual relatives. *See also* notes 18, 19, and 20, Chapter Four *infra*.

[11] This second aspect is discussed in pp. 91-94 *infra*.

situations patients are dependent and professionals are relatively powerful.[12] This disparity creates an obligation for professionals to reduce the understandable tendency of some patients to receive and act upon either a distorted understanding of their medical situation or a feeling of powerlessness, so that individuals can truly decide in accord with their own values and goals.[13]

Helping to shape the deliberations of a patient who must decide about the course and duration of his or her life is a complex and weighty obligation. For example, letting a patient know that his or her death is now seen by others to be appropriate—or at least not unexpected—may be "giving permission to die" to a patient who no longer wishes to struggle against overwhelming odds. On the other hand, it may encourage overly rapid acceptance of death by a patient who feels rejected and unimportant.[14]

Deciding on the best response and role is especially difficult for families and often inescapably uncertain. Clearly, family members do best by sustaining the patient's courage and hope, and by advancing the person's interests (and limiting self-serving actions) as much as possible. But family members usually cannot be dispassionate and emotionally uninvolved, nor should they try to be. In addition to any practical effects of the illness, they suffer from fear, anxiety, and grief—often as much or more than the patient. Thus, their ability to respond to the patient's needs is determined by their own capabilities under the circumstances.[15]

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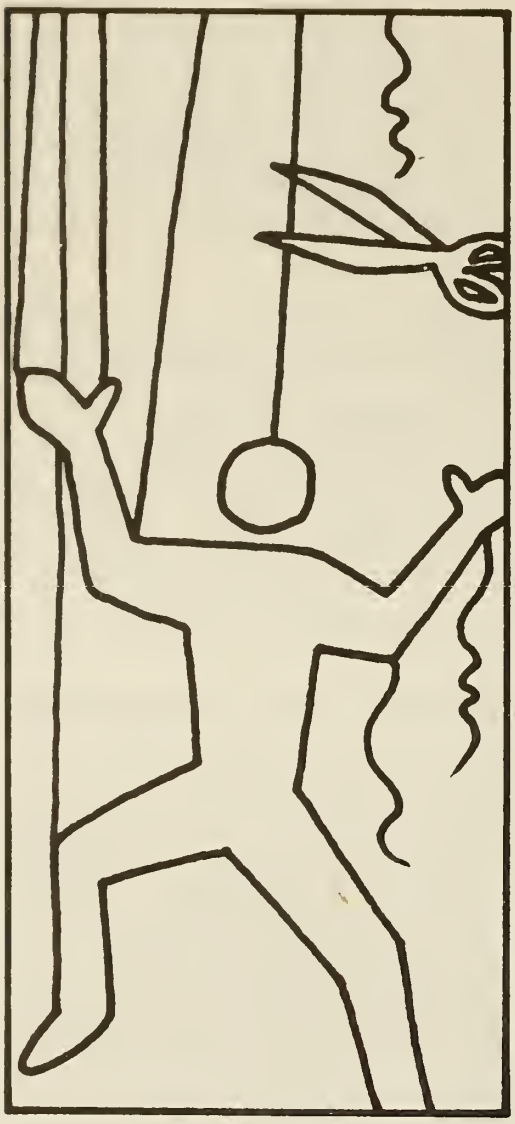
[12] Talcott Parsons, THE SOCIAL SYSTEM, The Free Press, New York (1951) at 445; Charles J. Dougherty and Sandra L. Dougherty, *Moral Reconstruction in the Hospital: A Legal and Philosophical Perspective on Patient Rights*, 14 CREIGHTON L. REV. 1409, 1423-24 (1981).

[13] This feeling of powerlessness led 27-year-old Ted Vergith, a paralyzed nursing home resident, to resist the recommended appointment of a guardian to consent to treatment for life-threatening infections: "I was not in control and I felt almost like I was being stripped of my dignity. Just because you can't walk anymore doesn't mean you can't think and make decisions for yourself." Although Vergith was successful in resisting the appointment of a guardian, he did accept treatment. 3 BIOETHICS LETTER 3 (Dec. 1982).

[14] Antipaternalistic policies may be construed in ways other than their proponents and practitioners intend. For example, if we do not intervene to prevent suicides out of respect for patient autonomy, our nonintervention may be seen as expressing the conviction that these deaths do not matter. A policy that affirms "you should care for yourself" may be interpreted as "we don't care for you."

James F. Childress, PRIORITIES IN BIOMEDICAL ETHICS, Westminister Press, Philadelphia (1981) at 32.

[15] Austin H. Kutscher, *Practical Aspects of Bereavement*, in Bernard Schoenberg *et al.*, eds., LOSS AND GRIEF: PSYCHOLOGICAL MANAGEMENT



Generally, part of the experience of dying involves withdrawing from some goals and relationships that have become unachievable or unimportant, pursuing other goals that are important to accomplish, providing directions for the future disposition of property and body, and giving advice to friends and families. Each of these practical steps entails reciprocal activities by others in a person's social network—acceptance of disengagement, support in revising priorities, legal counsel in writing a will, gathering for farewells, and so forth.[16]

The roles of health care professionals are different from those of family members. Their personal concerns and predispositions are not supposed to interfere with providing patients with competent care[17]; they are expected to develop ways to protect themselves from emotional exhaustion without becoming too distant or impersonal to help patients cope with emotional problems.[18]

The individual health care provider is likely to help dying patients most by maintaining a predisposition for sustaining life (while accepting that prolongation of dying may serve no worthwhile purpose for a particular patient). Indeed, this favoring of life is part of society's expectation regarding health care professionals.[19] Commonly, it is supported by a personal

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IN MEDICAL PRACTICE, Columbia Univ. Press, New York (1970) at 280; Henry J. Heimlich and Austin H. Kutscher, *The Family's Reaction to Terminal Illness*, in *id.* at 270.

[16] Barton E. Bernstein, *Lawyer and Therapist as an Interdisciplinary Team: Serving the Survivors*, 4 DEATH EDUCATION 179 (1980); Ann S. Kliman, *The Non-Legal Needs of a Dying Client*, NAT'L L.J., Nov. 24, 1980, at § 1-15.

[17] Different physicians often see the same situation quite differently, a fact that physicians ought to try to remedy as otherwise it severly biases patients' ability to choose. Robert A. Pearlman, Thomas S. Inui, and William B. Carter, *Variability in Physician Bioethical Decision-Making: A Case Study of Euthanasia*, 97 ANNALS INT. MED. 420 (1982).

[18] *See* note 57 *infra*.

[19] *See, e.g.*, Donald G. McCarthy, *The Responsibilities of Physicians*,

belief or value commitment and by a recognition of the needs of dying patients for reassurance about the worth of their own lives. Until it is quite clear that a patient is making an informed, deliberate, and voluntary decision to forego specific life-sustaining interventions, health care providers should look for and enhance any feelings the patient has about not yet acquiescing in death. As death comes closer, such sentiments generally recede; until then, there need be no haste to encourage a patient's acceptance of death.[20]

Enhancing the experience of those whose lives are drawing to a close is a worthwhile goal, one that requires skill, compassion, honesty, and humility. Here, various individuals can serve different and valued functions: clergy can attend especially to religious questions and rituals that affirm spiritual and temporal meaning; family members can resolve problems in relationships and reaffirm the importance of the patient's life; and health care professionals can focus on relieving immediate sources of distress and on enhancing the self-respect and courage of the patient.

The complex nature of provider-patient relations—each person influencing the attitudes of the other in ways that neither may fully understand—is illustrated by the case of "David G.," a young man who pleaded articulately with his physicians to cease the painful treatments they were providing for the extensive burns he had suffered.

> His sudden and unaccustomed total dependence on others insistently calls into question the psychological basis for common-sense perception that he has an identity separate from other people and from the external world.
>
> The critical ambiguity...goes...to Mr. G.'s conception of himself as a choice maker; that is, it is not clear whether he sees himself as separate from others in exercising choice regarding his future or whether he chooses death because he believes others want that result for him and he feels incapable of extricating himself from their choicemaking for him. Either perspective could lead to the deepest despair; his affliction itself could rob life of

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in Donald G. McCarthy and Albert S. Moraczewski, eds., MORAL RESPONSIBILITY IN PROLONGING LIFE DECISIONS, Pope John Center, St. Louis, Mo. (1981) at 255; John Ladd, *Physicians and Society: Tribulations of Power and Responsibility*, in Stuart F. Spicker, Joseph M. Healey, Jr., and H. Tristram Engelhardt, Jr., eds., THE LAW-MEDICINE RELATIONSHIP: A PHILOSOPHICAL EXPLANATION, D. Reidel Pub., Boston (1981) at 33.

[20] Ned H. Cassem, *Treatment Decisions in Irreversible Illness*, in Thomas P. Hackett and Ned H. Cassem, eds., MASSACHUSETTS GENERAL HOSPITAL HANDBOOK OF GENERAL HOSPITAL PSYCHIATRY, C.V. Mosby Co., St. Louis, Mo. (1978) at 572-73.

> all possible meaning for him: his belief that others...wished him dead could do the same. If, however, others were deferring to his wish to die because they conceived that they were honoring his self-determination, it would be critical to establish which of these two perspectives led him to this choice.[21]

Making choices available. Providers and others have an obligation to see that patients can choose among a range of available and potentially beneficial treatments.[22] Sometimes the range is limited wrongly because a practitioner is unwilling to make available an option or is ignorant of a possible treatment that is especially pertinent to a particular decision about life-sustaining therapy. Since competent and informed patients ought to be made aware that they can forego medical interventions, the option of no effort at curative therapy should generally be explored with dying patients. Some patients may associate this course with isolation, abandonment, and unmitigated suffering, however, unless supportive care is clearly also made available.

Good medical and nursing care can greatly improve the lives of patients who are dying.[23] Much comfort can be gained by careful attention to such details as proper positioning, vigorous skin care, oral hygiene, disguising of disfigurement, on-demand feeding of preferred foods, and so on. Medical management of symptoms has recently demonstrated that no patient should have to be terrified of physical pain; in fact, presently available drugs and techniques allow pain to be

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[21] Robert A. Burt, TAKING CARE OF STRANGERS, The Free Press, New York (1979) at 11. *See also* Robert B. White and H. Tristram Engelhardt, Jr., *A Demand to Die*, 5 HASTINGS CTR. REP. 9 (June 1975); Michael Platt, *Commentary: On Asking to Die*, 5 HASTINGS CTR. REP. 9 (Dec. 1975).

[22] For a discussion of external sources of unavailability, such as financial limitations on access to care, see Chapter Three *infra*.

[23] *See, e.g.*, Cicely Saunders, ed., THE MANGEMENT OF TERMINAL DISEASE, Edward Arnold Publishers, Ltd., London (1978); E. Mansell Pattison, ed., THE EXPERIENCE OF DYING, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1977). *See also* Appendix B, pp. 275-97 *infra*.

> We may do much good by a palliative course, by alleviating pain, procuring sleep, guarding the diet, regulating the alimentary canal—in fine, by obviating such sufferings as admit of mitigation...Lastly, by a just prognosis...we may sustain the patient and his friends during the inevitable course of the disease.

Jacob Bigelow, *Care in the Absence of Cure-1835, reprinted in* 85 ANNALS INT. MED. 825 (1976).

reduced to a level acceptable to virtually every patient, usually without unacceptable sedation.[24] Other symptoms, such as nausea, anxiety, constipation, and shortness of breath, usually respond reasonably well to drugs or other procedures.[25] Providers of care have an obligation to ensure that these supportive measures are available to everyone, whether or not a patient has chosen to pursue life-sustaining treatment. To allow such a decision to result in an avoidably harsh existence, or to let the patient believe that it will, is unjustifiable and may render the patient's decision involuntary.

Nonvoluntary decisionmaking. Nonvoluntary foregoing of life-sustaining therapy takes place when a patient gives neither effective consent nor refusal. Often this arises because a patient's decisionmaking capacity is inadequate, and then a surrogate will have to decide on behalf of the patient.[26] Sometimes, however, a patient, though competent, is excluded from the decisionmaking process. This is unjustifiable since it demeans the patient by barring self-determination and allows others to shorten the patient's life or establish the burdens under which it will be lived without the assurance (which could be obtained) that the patient concurs in the judgment. Although there may be times when a competent patient would prefer not to be involved in these choices, it is impossible to know in advance which patients would come to this conclusion.[27] And the risk of wrongly abrogating decisionmaking for many patients seems generally more grievous than the pain of confronting some seriously ill patients with choices that they would rather not face. The only time that the Commission finds it justified for a patient who could be informed and involved to be excluded is when that patient freely and knowingly transfers some decisionmaking authority to another.[28]

Informing and Communicating

Disclosure. The extent of the obligation of providers to inform patients so that they can make sound choices is no different for life-sustaining treatment than for any other. In the Commission's view, health professionals should ensure that patients understand (1) their current medical status, including

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[24] Robert G. Twycross, *Relief of Pain*, in Saunders, *supra* note 23, at 65; Ivan K. Goldberg, Sidney Malitz, and Austin H. Kutscher, eds., PSYCHOPHARMACOLOGIC AGENTS FOR THE TERMINALLY ILL AND BEREAVED, Columbia Univ. Press, New York (1973).

[25] *See, e.g.*, Mary J. Baines, *Control of Other Symptoms*, in Saunders, *supra* note 23, at 99. *See also* Appendix B, pp. 275-97 *infra*.

[26] *See* pp. 126-31 *infra*.

[27] MAKING HEALTH CARE DECISIONS, *supra* note 1, at 94-102. One regular exception to this is that most people willingly let professionals make decisions for them when life-sustaining treatment is needed on an emergency basis. *Id.* at 93.

[28] *Id.* at 50-51.

its likely course if no treatment is pursued; (2) the interventions that might be helpful to the patient, including a description of the procedures involved and the likelihood and effect of associated risks and benefits; and (3) in most cases, a professional opinion as to the best alternative.[29] Each of these elements must be discussed in light of associated uncertainties.[30]

The purpose of such discussions is not to inundate patients with medical facts but rather to give them the information they need in order to assess options realistically and to choose the treatments most consonant with their own values and goals. Inaccurate or incomplete information limits patients' understanding of what is at stake. For any medical intervention to be warranted, a patient must stand to gain more from having the treatment than from not having it. Since the benefit to be gained must be assessed in terms of the patient's own values and goals, practitioners should be cautious not to rule out prematurely a seemingly undesirable or less-than-optimal alternative that might offer what a particular patient would perceive as a benefit.

Physician attitudes toward communication with terminally ill patients have changed dramatically in recent years. Whereas 20 years ago the majority of physicians did not disclose a fatal diagnosis to their patients, most physicians now do so routinely.[31] Yet both behaviors—generally withholding in the 1960s and generally disclosing today—seem to be based on physicians' judgments of what is best for patients rather than on recognition of the value of self-determination per se.

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[29] A physician who merely spreads an array of vendibles in front of the patient and then says, "Go ahead and choose, it's your life," is guilty of shirking his duty, if not of malpractice. The physician, to be sure, should list the alternatives and describe their pros and cons but then, instead of asking the patient to make the choice, the physician should recommend a specific course of action. He must take the responsibility, not shift it onto the shoulders of the patient. The patient may then refuse the recommendation, which is perfectly acceptable, but the physician who would not use his training and experience to recommend the specific action to a patient—or in some cases frankly admit "I don't know"—does not warrant the somewhat tarnished but still distinguished title of doctor.

Franz J. Ingelfinger, *Arrogance*, 303 New Eng. J. Med. 1507, 1509 (1980). *See also* Making Health Care Decisions, *supra* note 1, at 76-79.

[30] Making Health Care Decisions, *supra* note 1, at 85-89. *See also* Parsons, *supra* note 12, at 449; Renée C. Fox, *The Evolution of Medical Uncertainty*, 58 Milbank Mem. Fund Q./Health & Society 1, 49 (1980).

[31] Dennis H. Novack *et al., Changes in Physicians' Attitudes Toward Telling the Cancer Patient*, 241 J.A.M.A. 897 (1979).

Three surveys between 1953 and 1961,[32] for example, found that 69-90% of physicians routinely failed to inform cancer patients of their diagnosis, claiming that the unvarnished truth would be too much for their patients—"a death sentence," "torture," or "hitting the patients with a baseball bat."[33] Those surveyed expressed concern about the psychological damage that could ensue from such revelations[34] and gave that as a reason for a "therapeutic privilege" to exempt them from the requirements of informed consent when caring for terminally ill patients.[35] Yet one researcher found "on closer examination, most of the instances in which unhappy results were reported to follow [disclosure] turned out to be vague accounts from which no reliable inference could be drawn."[36] Fearful of the effects of telling the truth, many physicians relied upon incomplete information and euphemisms, resorting to vague terms such as "lesion" or "mass" or using language only suggestive of malignancy, such as a "suspicious" or "degenerated" tumor.[37]

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[32] William T. Fitts, Jr. and I.S. Ravdin, *What Philadelphia Physicians Tell Patients with Cancer*, 153 J.A.M.A. 903 (1953); Dan Rennick, *What Should Physicians Tell Cancer Patients?*, New Med. Materia 51 (March 1960); Donald Oken, *What to Tell Cancer Patients: A Study of Medical Attitudes*, 175 J.A.M.A. 1120 (1961).

[33] Oken, *supra* note 32, at 1125.

[34] The reluctance to disclose information shown by the early surveys seemed ironic in the face of the desire expressed by the overwhelming majority of physicians to be told when they themselves confront serious illness. Herman Feifel, *The Function of Attitudes Toward Death*, in Death and Dying: Attitudes of Patient and Doctor, Symposium #11, Group for the Advancement of Psychiatry, New York 632, 635 (1965). Interestingly, however, they still would not disclose such information to their physician brethren. Jay Katz and A. M. Capron, Catastrophic Diseases: Who Decides What?, Russell Sage Foundation, New York (1975) at 101 n.56.

[35] Hubert W. Smith, *Therapeutic Privilege to Withhold Specific Diagnosis from Patient Sick with Serious or Fatal Illness*, 19 Tenn. L. Rev. 349 (1946).

[36] Oken, *supra* note 32, at 1124.

[37] *Id.* at 1125. The practice of using misleading euphemistic language has apparently long existed, as can be seen in a well-known nineteenth-century work:

> The face of a physician, like that of a diplomatist should be impenetrable. Nature is a benevolent old hypocrite; she cheats the sick and dying with illusions better than any anodynes....
>
> Some shrewd old doctors have a few phrases always on hand for patients that will insist on knowing the pathology of their complaints without the slightest capacity of understanding the scientific explanation. I have known the term "spinal irritation" serve well on such occasions, but I think nothing on the whole has covered so much ground, and meant so little, and given such profound satisfaction to all parties, as the magnificient

In a 1978 replication of the 1961 survey, 97% of physicians said they preferred to tell cancer patients of their diagnosis, compared with only 10% of those polled earlier.[38] Physician attitudes thus now seem to be more attuned to current desires of patients, the overwhelming majority of whom want to know the whole truth. Indeed, in the Commission's survey of patient-provider relationships, "the public displayed an unflinching desire for facts about their condition, even dismal facts"; 96% of the public stated specifically that they would want to know of a diagnosis of cancer, and 86% said they would want a realistic prognosis.[39]

There are a number of hypotheses about why physicians' attitudes shifted. When physicians avoided telling patients their prognoses explicitly, they may still have found that patients arrived at quite reliable conclusions about the nearness of death from how sick they were and from the behavior of others. In one study, three-fourths of the patients who had not been fully informed nevertheless knew that they were expected to die soon.[40] When this is the case, the issue of

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phrase "congestion of the portal system."
Oliver Wendell Holmes, *The Young Practitioner*, in MEDICAL ESSAYS: 1842-1892, Houghton Mifflin and Co., Boston (1891) at 370, 388-89.

[38] Physicians in the 1978 survey cited the patient's age, intelligence, and emotional stability, in addition to the patient's or relatives' expressed wishes to be told, as factors in deciding whether to disclose. Obviously, reliance on these qualifiers as hurdles patients must overcome to receive information could lead to objectionable paternalism. Novack, *supra* note 31.

Regarding intelligence as a prerequisite, one physician, writing in a popular magazine, had this observation: "To some highly intelligent people—like John Foster Dulles or Robert A. Taft—you can tell the simple truth and know that it is not going to destroy them as human beings. Their minds... are capable of ...adjusting to it rationally." *Discussion, Should Doctors Tell the Truth to a Cancer Patient?*, 78 LADIES HOME J. 65, 108 (May 1961). The wiser view would seem to be that "It is very probable that a doctor feels better able to tell an intelligent patient, but this does not necessarily mean that the less intelligent may not cope with this knowledge as well." John M. Hinton, *The Physical and Mental Distress of the Dying*, 32 Q.J. MED. 1, 19 (1963). For a critique of paternalistic justifications for withholding information from patients, see Allen E. Buchanan, *Medical Paternalism*, in Marshall Cohen *et al.*, eds., MEDICINE AND MORAL PHILOSOPHY, Princeton Univ. Press, Princeton, N.J. (1982) at 214.

[39] Louis Harris and Associates, *Views of Informed Consent and Decisionmaking: Parallel Surveys of Physicians and the Public*, in President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, MAKING HEALTH CARE DECISIONS, VOLUME TWO: APPENDICES (EMPIRICAL STUDIES OF INFORMED CONSENT), U.S. Government Printing Office, Washington (1982) at 17.

[40] Hinton, *supra* note 38, at 19.

whether the doctor should tell the patient loses much of its force. Moreover, most of the surveys have dealt with cancer,[41] which may indeed have been very nearly a death sentence as recently as two decades ago. Today remission and even cure is often possible; the disease is not as ominous or stigmatizing as it once was.[42] Since the medical information is more complex, diagnoses today may actually need much more explanation in order for patients to understand the relevant facts.

Physicians may also be giving more information as a function of the increasingly broad and enforced legal duties of disclosure.[43] And many dying patients are part of clinical research in which the obligation to disclose a diagnosis before consent is obtained is carefully enforced by each hospital's institutional review board.[44] Finally, physicians have doubtless been affected by the desire of terminally ill patients for more information, one manifestation of an era marked by consumerism, "patients' rights," and a wariness of the professions generally.

Some physicians are more willing to talk about dying because they have seen the detrimental effects of not doing so. Failure to disclose information to patients who seek it takes a toll in the erosion of trust—the basic bond between physician and patient. This mistrust is likely to be exacerbated and extended to family members if they conspire in keeping silent.[45] For patients whose intuitions tell them they are

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[41] *See, e.g.*, notes 21 and 32 *supra*; William D. Kelly and Stanley R. Frisen, *Do Cancer Patients Want to Be Told?*, 27 SURGERY 822 (1950); E.M. Litin, *Should the Cancer Patient be Told?*, 28 POSTGRADUATE MED. 470 (1960); Robert J. Saup and Anthony R. Curreric, *A Questionnaire Survey on Public Cancer Education Obtained from Cancer Patients and Their Families*, 10 CANCER 382 (1957); Lesley A. Slavin, *Communication of the Cancer Diagnosis to Pediatric Patients: Impact on Long-term Adjustment*, 139 AM. J. PSYCHIATRY 179 (1982).

[42] For an elucidation of some of the myth, metaphor, and imagery surrounding cancer, see Susan Sontag, ILLNESS AS METAPHOR, Farrar, Straus & Giroux, New York (1978).

[43] Note, *Informed Consent and the Dying Patient*, 83 YALE L. J. 1632 (1974); Arnold J. Rosoff, INFORMED CONSENT: A GUIDE FOR HEALTH CARE PROVIDERS, Aspen Systems Corporation, Rockville, Md. (1981). One example of a statutory duty to disclose a terminal diagnosis is the District of Columbia's Natural Death Act, which requires a physician to inform the patient of his or her terminal condition verbally or in writing so that the Act's provisions have legal force. D.C. Code Ann. tit. 16, § 6-2425(b) (1981), *reprinted in* Appendix D, pp. 335-40 *infra*.

[44] Emil J. Freireich, *Should the Patient Know?*(Editorial), 241 J.A.M.A. 928 (1979); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, THE OFFICIAL IRB GUIDEBOOK, U.S. Government Printing Office, Washington (1983).

[45] This danger is revealed movingly in the case of Jo Ann Mortenson, a 37-year old woman from whom a diagnosis of brain tumor was withheld. Her family was told the truth; Jo Ann was told she had an

seriously ill, unlikely fabrications or euphemisms may result in fear that the doctor does not know the real diagnosis or that the family cannot cope with it. For many, the worry, conjecture, and degradation that can result from misinformation may be more tormenting than the knowledge of the illness itself.[46] Nondisclosure may inhibit further questions from patients, which would limit their capacity to participate in medical care decisions as well as those on other personal and financial affairs.

The issue of whether to tell patients about a terminal diagnosis is less a choice of "to tell or not to tell" than it is a question of how to gauge how much each patient wants to

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"encephalitic scar." She later said:

> Imagine taking the parents of a thirty-seven-year-old woman and a man who is the father of five children into a room, hitting them over the head with the truth and then expecting them to take the responsibility for what should be told to the patient. That's not fair. When the doctor takes on the patient in the first place, he is taking the patient on whether that patient lives or dies; and when something unpleasant comes up, it is the doctor's job to tell the patient.
>
> Perhaps he might start off before he knows the results of any tests and ask if the patient wants to know the truth. He can remind the patient that whatever the diagnosis, he is prepared to be available as long as the patient requires, to supply whatever physical and psychological comfort he can.

Gerald Astor, *"What's Really Wrong with Me?,"* 100 McCall's 52, 138 (June 1973). *See also* Peter Maguire, *The Personal Impact of Dying*, in Eric Wilkes, ed., The Dying Patient, George A. Bogden & Son, Inc., Ridgewood, N.J. (1982) at 233, 252; W.P.L. Myers, *The Care of the Patient with Terminal Illness*, in Paul B. Beeson, Walsh McDermott, and James B. Wyngaarden, eds., Cecil Textbook of Medicine, W.B. Saunders Co., Philadelphia (1979) at 1941, 1944.

[46] What tormented Ivan Ilych most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and that he only need keep quiet and undergo a treatment and then something very good would result. He however knew that do what they would nothing would come of it, only still more agonizing suffering and death. This deception tortured him—their not wishing to admit what they all knew and what he knew, but wanting to lie to him concerning his terrible condition, and wishing and forcing him to participate in that lie. Those lies—lies enacted over him on the eve of his death and destined to degrade this awful, solemn act to the level of their visitings, their curtains, their sturgeon for dinner—were a terrible agony for Ivan Ilych.

Leo Tolstoy, *The Death of Ivan Ilych*, in The Death of Ivan Ilych and Other Stories, New American Library, New York (Aylmer Maude trans., 1960) at 95, 137. *See also* William F. May, *On Not Facing Death Alone*, 1 Hastings Ctr. Rep. 8 (June 1971).

know at a particular time. As one experienced physician has noted, "The real question is not 'what do you tell your patients?' but rather 'what do you let your patients tell you?'"[47] In other words, "Now that we tell our patients more, are we also listening more?"[48]

Clearly, doses of truth must be administered with sensitivity, lest they inflict undue psychic trauma upon patients. The dialetic of provider-patient communication is a sensitive one that varies from case to case.[49] Commonly, communication and cues take nonverbal forms, and verbal expressions sometimes are misleading. Meaningful dialogue does not come easily or cheaply:

> You have to be prepared to spend an enormous amount of time with that person, exploring and talking and being quiet for periods of time and letting conversation go and coming back to conversation....Expenditure of time is something that is a quite precious commodity in medical care generally, and is in fact ladled out rather sparingly...particularly with dying patients.[50]

A nurse who has worked with parents of seriously ill newborns in a neonatal intensive care unit told the Commission:

> Very often parents are not ready to talk a great deal initially about the worst and most horrible possibilities for the future of their child. And so a good deal of time is often spent in early weeks...on what sounds like casual chitchat. I talked a lot about baseball and TV and other things with this family...which really was contributory to building the relationship to use when we needed it.[51]

Learning to communicate. For professionals who work with the dying, as well as for families and loved ones, being with patients who are dying can be painful and emotionally exhausting; in truth, it means facing one's own death.

> It extracts a cost that is usually overlooked in the training of the professional. In fact, it would be more accurate to say that the cost is known but the student is

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[47] Cicely Saunders, *The Moment of Truth: Care of the Dying Person*, in L. Pearson, ed., DEATH AND DYING, Case Western Reserve Univ. Press, Cleveland, Ohio (1969) at 49, 59.

[48] Novack, *supra* note 31, at 899. *See also*, E.R. Hillier, *Communication Between Doctor and Patient*, in Robert G. Twycross and Vittorio Ventafridda, eds., THE CONTINUING CARE OF TERMINAL CANCER PATIENTS, Pergamon Press, New York (1980) at 37.

[49] *See* Ned H. Cassem, *The Dying Patient*, in Hackett and Cassem, *supra* note 20, at 300.

[50] Testimony of Robert Burt, transcript of 21st meeting of the President's Commission (June 10, 1982) at 169.

[51] Testimony of Carole Kennon, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 21-22.

> usually warned against paying it. The price of compassion is conveyed by the meaning of the two words, *com* and *passio*, which mean to "suffer *with*" another person. One must be touched by the tragedy of the patient in a literal way, a process that occurs through experiential identification with the dying person. This process, empathy, when evoked by a person facing death or tragic disability, ordinarily meets strong...resistance. Who can bear the thought of dying at 20?[52]

For some, avoidance is a way to deal with disconcerting aspects of being with dying patients. Such avoidance can be an impersonal or scientific attitude as much as a failing to be physically present.[53] Patients often express concern about loneliness in their final days, and studies have showed that many professionals tend to avoid dying patients.[54] When this occurs, the patient can end up in a netherworld of neglect, feeling lonely and abandoned; possibly foregoing opportunities to receive palliative, comforting measures; perhaps even missing the chance that a mistaken diagnosis will be corrected.[55]

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[52] Ned H. Cassem and Rege S. Stewart, *Management and Care of the Dying Patient*, 6 INT'L. J. PSYCHIATRY IN MED. 293, 298 (1975).

> [53] To Ivan Ilych only one question was important: was his case serious or not? But the doctor ignored that inappropriate question. From his point of view it was not the one under consideration, the real question was to decide between a floating kidney, chronic catarrh, or appendicitis. It was not a question of Ivan Ilych's life or death.

Tolstoy, *supra* note 46, at 121.

[54] One dying patient stated: "I feel like a railway station that's been closed down—the ward round doesn't stop here any more." Michael A. Simpson, *Therapeutic Uses of Truth*, in Wilkes, *supra* note 45, at 255, 259. *See also* Barney G. Glaser and Anselm L. Strauss, *Dying on Time*, in Anselm L. Strauss, ed., WHERE MEDICINE FAILS, Aldine Pub. Co., Hawthorne, N.Y. (1970) at 131, 139; Donald G. Gallup, Marco Labudovich, and Paul R. Zambito, *The Gynecologist and the Dying Cancer Patient*, 144 AM. J. OBSTET. GYNECOL. 154 (1982); *Physicians Found to Spend Little Time With Oldsters*, 22 MED. WORLD NEWS 48 (Aug. 17, 1981); David Rabin, Pauline L. Rabin, and Roni Rabin, *Compounding the Ordeal of A.L.S.: Isolation from My Fellow Physicians*, 307 NEW ENG. J. MED. 506 (1982).

> [55] After the flurry of attention to the diagnosis [carcinoma], ward personnel lost interest. The patient began to be moved further and further from the nursing station at the front of the ward. The withdrawal that our patient experienced was not so much physical absence as uninterest....[An autopsy revealed] a tumor that should have readily yielded to the correct neurosurgical attack.

Charles D. Aring, *Intimations of Immortality*, 69 ANNALS INT. MED. 137, 140 (1968).

Of course, dying patients may be difficult to work with and their mental and physical state may be such that communication takes longer than with other patients. Also, avoiding such patients on occasion might be respecting their wish not to be disturbed. Yet if health care professionals recognize that the tendency toward avoidance exists, they can then seek to mitigate its impact themselves and to involve other care givers, including clergy. The importance of teamwork and mutual support among those who work with the dying has been demonstrated in hospices and neonatal intensive care units.[56] Having colleagues who are willing to listen and a forum in which to express one's feelings can help deal with the emotional toll of working with the dying. A tendency to "burnout" after extended periods of such work has been noted, though there are strategies to help cope with this.[57]

Some medical and nursing schools never deal with dying as a subject, and some do so all too shallowly. One professor of psychiatry and family practice reported:

> In the School of Nursing I encountered,...the junior nurses were given a half-hour lecture on the Kübler-Ross five, and were then sent to the bedsides of terminally ill patients with the instructions to "get them through to acceptance" in an hour.[58]

The notion that a bit of brief classroom work can transform providers into sensitive humanitarians and effective communicators is, of course, simplistic and dangerous. The training of health care professionals should include serious and systematic attention to the requisite skills for working with dying patients. Whereas only 50 years ago it was the rare household that had not been touched by death, today many students in professional training have not previously been exposed to a dying person. Even medical students and residents are likely during their years of clinical training to miss the chance to attend for any length of time a patient in the shadow of impending death. Indeed, many physicians and nurses have never stayed with a dying patient through the final

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[56] Thelma D. Bates, *At Home and in the Ward: The Establishment of a Support Team in an Acute Care General Hospital*, in Wilkes, *supra* note 45, at 263; Kennon, *supra* note 51, at 31; *see also* note 89, Chapter Six *infra*.

[57] *See* Stephen B. Shanfield, *The Mourning of the Health Care Professional: An Important Element in Education about Death and Loss*, 4 DEATH EDUCATION 385 (1981); Louis E. LaGrand, *Reducing Burnout in the Hospice and the Death Education Movement*, 4 DEATH EDUCATION 61 (1980); Glaser and Strauss, *supra* note 54, at 34; Richard A. Kolotkin, *Preventing Burn-Out and Reducing Stress in Terminal Care: The Role of Assertive Training*, in Harry J. Sobel, ed., BEHAVIOR THERAPY IN TERMINAL CARE: A HUMANISTIC APPROACH, Ballinger Pub. Co., Cambridge, Mass. (1981) at 229; Cassem, *supra* note 49.

[58] Simpson, *supra* note 54, at 259.

few hours and have never actually seen a patient die except in an unsuccessful resuscitation effort.

Empirical evidence has shown that many of the skills needed to work with the dying can be learned, while undesirable responses and reactions such as avoidance can be "unlearned" or mitigated.[59] Some health care professionals have cited their lack of such training as an impediment in caring for dying patients.[60]

Educating providers to become better communicators is a process that is both explicit and implicit.[61] Work in formal courses is unlikely to have any impact unless it is validated by behaviors at the bedside. Young physicians and nurses need to see their mentors doing the hard work of attending the dying; they are unlikely to learn if all their role models are people only a few years their senior professionally, especially since, as the Commission found, younger physicians are less likely to be comfortable discussing "dismal" news with their patients.[62]

Educational reform must entail greater change than adding a dash of the humanities to already overburdened health care curricula. What is needed instead is systematic attention to the social, ethical, psychological, and organizational aspects of caring for dying patients. Students should also be encouraged to develop an appreciation for different patterns and styles of dying, especially as they arise from different cultures, medical care settings, or religious views.

Reexamining the Role of Traditional Moral Distinctions

Most patients make their decisions about the alternative courses available to them in light of such factors as how many days or months the treatment might add to their lives, the nature of that life (for example, whether treatment will allow or interfere with their pursuit of important goals, such as completing projects and taking leave of loved ones), the degree of suffering involved, and the costs (financial and otherwise) to themselves and others. The relative weight, if any, to be given to each consideration must ultimately be determined by the competent patient.

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[59] Margaret Shandor Miles, *The Effect of a Course on Death and Grief on Nurses' Attitudes Toward Dying Patients and Death*, 4 DEATH EDUCATION 245 (1980); George E. Dickinson, *Death Education in U.S. Medical Schools: 1975-1980*, 56 J. MED. EDUC. 111 (1981).

[60] *See, e.g.*, Loretta Hoggatt and Bernard Spilka, *The Nurse and the Terminally Ill Patient: Some Perspectives and Projected Actions*, 9 OMEGA 255 (1978).

[61] MAKING HEALTH CARE DECISIONS, *supra* note 1, at 135.

[62] *Id.* at 96.

Other bases are sometimes suggested for judging whether life-and-death decisions about medical care are acceptable or unacceptable beyond making sure that the results of the decisions are justified in the patient's view by their expected good. These bases are traditionally presented in the form of opposing categories. Although the categories—causing death by acting versus by omitting to act; withholding versus withdrawing treatment; the intended versus the unintended but foreseeable consequences of a choice; and ordinary versus extraordinary treatment—do reflect factors that can be important in assessing the moral and legal acceptability of decisions to forego life-sustaining treatment, they are inherently unclear. Worse, their invocation is often so mechanical that it neither illuminates an actual case nor provides an ethically persuasive argument.[63]

In considering these distinctions, which are discussed in detail in the remainder of this chapter, the Commission reached the following conclusions, which are particularly relevant to assessing the role of such distinctions in public policies that preclude patients and providers from choosing certain options.

- The distinction between acting and omitting to act provides a useful rule-of-thumb by separating cases that probably deserve more scrutiny from those that are likely not to need it. Although not all decisions to omit treatment and allow death to occur are acceptable, such a choice, when made by a patient or surrogate, is usually morally acceptable and in compliance with the law on homicide; conversely, active steps to end life, such as by administering a poison, are likely to be serious moral and legal wrongs. Nonetheless, the mere difference between acts and omissions—which is often hard to draw in any case—never by itself determines what is morally acceptable. Rather, the acceptability of particular actions or omissions turns on other morally significant considerations, such as the balance of harms and benefits likely to be achieved, the duties owed by others to a dying person, the risks imposed on others in acting or refraining, and the certainty of outcome.
- The distinction between failing to initiate and stopping therapy—that is, withholding versus withdrawing treatment—is not itself of moral importance. A justification that is adequate for not commencing a treatment is also sufficient for ceasing it. Moreover,

[63] Such terms are also used in varying ways. In particular, some people may use a term (such as "allowing to die" or "artificial means") descriptively while others attach a normative connotation to the same phrase.

erecting a higher requirement for cessation might unjustifiably discourage vigorous initial attempts to treat seriously ill patients that sometimes succeed.

- A distinction is sometimes drawn between giving a pain-relieving medication that will probably have the unintended consequence of hastening a patient's death and giving a poison in order to relieve a patient's suffering by killing the patient. The first is generally acceptable while the latter is against the law. Actions that lead to death must be justified by benefits to the patient that are expected to exceed the negative consequences and ordinarily must be within the person's socially accepted authority. In the case of physicians and nurses, this authority encompasses the use of means, such as pain-relieving medication, that can cure illnesses or relieve suffering but not the use of means, such as weapons or poisons, whose sole effect is viewed as killing a patient.
- Whether care is "ordinary" or "extraordinary" should not determine whether a patient must accept or may decline it. The terms have come to be used in conflicting and confusing ways, reflecting variously such aspects as the usualness, complexity, invasiveness, artificiality, expense, or availability of care. If used in their historic sense, however—to signify whether the burdens a treatment imposes on a patient are or are not disproportionate to its benefits—the terms denote useful concepts. To avoid misunderstanding, public discussion should focus on the underlying reasons for or against a therapy rather than on a simple categorization as "ordinary" or "extraordinary."

The analysis of these four distinctions in this chapter need not be repeated in decisionmaking for each individual patient. Rather, the Commission intends to point to the underlying factors that may be germane and helpful in making decisions about treatment or nontreatment and, conversely, to free individual decisionmaking and public policy from the mistaken limitations imposed when slogans and labels are substituted for the careful reasoning that is required.

Acting Versus Omitting to Act. For many dying patients who decide to forego further life-prolonging treatment when its benefits no longer seem to them worth the burdens it creates, cessation of treatment leads rapidly to an end of life and, with that, to a release from their suffering. Others, however, suffer from conditions that would not be immediately fatal were treatment withdrawn. Some of these patients wish that they (or someone acting at their request) could administer a poison to end their suffering more quickly. The Commission does not

believe that society ought to condone the deliberate use of poisons or similar lethal agents in this setting. To do so would certainly risk serious abuse.

Lawyers, health care professionals, and policymakers today are in general accord that treatment refusals by dying patients should be honored.[64] Physicians commonly acquiesce in the wishes of competent patients not to receive specified treatments, even when failure to provide those treatments will increase the chance—or make certain—that the patient will die soon.[65] When some patients are dying of a disease process that cannot be arrested, physicians may, for example, write orders not to provide resuscitation if the heart should stop,[66] forego antibiotic treatment of pneumonia and other infections,[67] cease use of respirators,[68] or withhold aggressive therapy from overwhelmingly burned patients.[69] Courts have sanctioned such decisions by guardians for incompetent patients,[70] as well as by competent patients who might have lived for an indefinite period if treated.[71] Although declining to start or continue life-sustaining treatment is often acceptable, health care providers properly refuse to honor a patient's request to be directly killed. Not only would killing, as by violence or strychnine, be outside the bounds of accepted medical prac-

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[64] *See, e.g.*, John A. Robertson, THE RIGHTS OF THE CRITICALLY ILL, Bantam Books, New York (1983) at 23; William J. Monahan, *Contemporary American Opinion On Euthanasia*, in McCarthy and Moraczewski, *supra* note 19, at 180.

[65] *See, e.g.*, Testimony of Dr. Anne Fletcher, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 8, 26; Testimony of Dr. Ned Cassem, S.J., transcript of 10th meeting of the President's Commission (June 4, 1981) at 74; Testimony of Dr. Richard Scott, transcript of 12th meeting of the President's Commission (Sept. 12, 1981) at 398.

[66] *See* pp. 244-47 *infra*.

[67] *See* Appendix B pp. 275-97 *infra*; Norman K. Brown and Donovan J. Thompson, *Nontreatment of Fever in Extended-Care Facilities*, 300 NEW ENG. J. MED. 1246 (1979).

[68] *See, e.g.*, Ake Grenvik, *Terminal Weaning: Discontinuance of Life-Supporting Therapy in the Terminally Ill Patient*, 11 CRIT. CARE MED. (forthcoming, May 1983). *See also, In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

[69] Sharon H. Imbus and Bruce E. Zawacki, *Autonomy for Burn Patients When Survival Is Unprecedented*, 297 NEW ENG. J. MED. 308 (1977).

[70] *See, e.g., In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976); *In re* Dinnerstein, 380 N.E.2d 134 (Mass. App. Ct. 1978); Superintentent of Belchertown State School v. Saikewicz, 370 N.E.2d 417 (1977). *See also* David W. Meyers, MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING, The Lawyers Co-operative Pub. Co., Rochester, N.Y. (1981) at 211-62; pp. 121-31 *infra*.

[71] *See, e.g.*, Satz v. Perlmutter, 379 So.2d 359 (Fla. 1980); Lane v. Candura, 376 N.E.2d 1232 (Mass. App. 1978); *In re* Quackenbush, 383 A.2d 785 (N.J., Morris County Ct. 1978).

tice, but as murder it would be subject to a range of criminal sanctions, regardless of the provider's motives.[72]

In both scholarly and policy discussions, "killing" is often equated with an action causing death, and "allowing to die" with an omission causing death.[73] Killing and allowing to die are then used as merely descriptive terms, leaving open which actual actions that cause death (that is, killings) are morally wrong. Certainly some actions that cause death, such as self-defense, are morally justified. However, particularly in medicine, "killing" is often understood to mean actions that *wrongfully* cause death, and so is never justifiably done by health care providers. Likewise, "allowing to die" is often used to communicate *approval* of accepting that death will occur rather than simply to describe the behavior.[74] In an attempt to avoid confusion that stems from these conflicting usages and to present the important issues clearly, the Commission's discussion employs the descriptive terms—actions that lead to death and omissions that lead to death—rather than mixing the normative and descriptive connotations of the terms killing and allowing to die.

Although the Commission believes that most omissions that lead to death in medical practice are acceptable, it does not believe that the moral distinction between that practice and wrongful killing lies in the difference between actions and omissions per se. Not only is this distinction often difficult to draw in actual practice, it fails to provide an adequate foundation for the moral and legal evaluation of events leading to death. Rather, the acceptability or unacceptability of conduct turns upon other morally significant factors, such as

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[72] *See* p. 33 *supra*.

[73] *See, e.g.*, James Rachels, *Active and Passive Euthanasia*, 292 New Eng. J. Med. 78 (1975); Tom Beauchamp, *A Reply to Rachels on Active and Passive Euthanasia*, in Tom Beauchamp and Seymour Perlin, eds., Ethical Issues in Death and Dying, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1978) at 246; Sisella Bok, *Death and Dying: Euthanasia and Sustaining Life: Ethical Views*, in 1 Encyclopedia of Bioethics, at 268; Harold F. Moore, *Acting and Refraining*, in *id.* at 38. The philosophical and moral issues concerning the nature and significance of the killing-letting die distinction are extensively explored in Bonnie Steinbock, ed., Killing and Letting Die, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1980); P. J. Fitzgerald, *Acting and Refraining*, in Samuel Gorovitz *et al.*, eds., Moral Problems in Medicine, Prentice-Hall, Inc., Englewood Cliffs, N. J. (1976) at 284. *See also* Jonathan Glover, Causing Death and Saving Lives, Penguin Books, New York (1977) at 92.

[74] George Fletcher, *Prolonging Life*, 42 Wash. L. Rev. 999 (1967); Edward J. Gurney, *Is There a Right to Die? A Study of the Law of Euthanasia*, 3 Cum.-Sam. L. Rev. 235 (1972); Robert S. Morrison, *Alternatives to Striving Too Officiously*, in Franz J. Ingelfinger *et al.*, eds., Controversy in Internal Medicine II, W.B. Saunders, Philadelphia (1974) at 113.

the duties owed to patients, the patients' prospects and wishes, and the risks created for someone who acts or who refrains from acting.

The difference between actions and omissions that lead to death. The distinction between acts and omissions is often easy to draw. A person acts in a way that results in another's death, for example, by fatally poisoning an otherwise healthy person. On the other hand, a person's omission leads to the death of another if the first person knows he or she has the ability and opportunity to act so as to prevent the other dying (at a particular time and in a particular way)[75] but refrains from doing so. For example, an omission leads to death when a person could, but does not, rescue a nearby child who is drowning. The difference, then, is that when A acts to cause B to die, the course of events into which A's action intervenes is otherwise one in which B is not likely to die, whereas when A omits to act and thus causes B to die, the course of events already under way (into which A fails to intervene) includes B's imminent death. Thus, the distinction between a fatal act and a fatal omission depends both upon the difference between a person physically acting and refraining from acting and upon what might be called the background course of events.

If a patient's death is imminent (for example, death is expected within a matter of days) failing to treat and thus hastening death is seen by some not even to be a case of an omission that leads to death—failing to treat is said to be merely "avoiding prolonging the dying process."[76] To hold that such a failure to treat is neither a fatal act nor an omission is wrong and misleading. No one can prevent a person's ever dying; death can only be postponed by preventing it at the moment. Usually, though not always, to postpone death for only a very short time is less important, but that is relevant to whether an omission is wrong and how serious the wrong is, not to whether it is an omission that leads to a patient's death.

Sometimes deciding whether a particular course involves an act or an omission is less clear. Stopping a respirator at the request of a competent patient who could have lived with it for a few years but who will die without it in just a few hours is

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[75] More formally, it can be said that the deceased would not have died as and when he or she did had the person responsible not acted in the way he or she did. For death to be a killing by another, that other's action must have changed the cause of the person's death, or have hastened the moment of death, or both.

[76] *See, e.g.*, Glover, *supra* note 73, at 197; James B. Nelson, HUMAN MEDICINE: ETHICAL PERSPECTIVES ON NEW MEDICAL ISSUES, Augsburg Pub. House, Minneapolis, Minn. (1973) at 125; Natural Death statutes for Alabama, the District of Columbia, and Kansas, *reprinted in* Appendix D, pp. 318-23, 335-40, 345-49 *infra*.

such an ambiguous case. Does the physician omit continuing the treatment or act to disconnect it? Discontinuing essential dialysis treatments or choosing not to give the next in a sequence of antibiotic doses are other events that could be described either as acts or omissions.

The moral significance of the difference. Actual instances of actions leading to death, especially outside the medical context, are more likely to be seriously morally wrong than are omissions that lead to death, which, in the medical context, are most often morally justified. Usually, one or more of several factors make fatal actions worse than fatal omissions:

(1) The motives of an agent who acts to cause death are usually worse (for example, self-interest or malice) than those of someone who omits to act and lets another die.

(2) A person who is barred from acting to cause another's death is usually thereby placed at no personal risk of harm; whereas, especially outside the medical context, if a person were forced to intercede to save another's life (instead of standing by and omitting to act), he or she would often be put at substantial risk.

(3) The nature and duration of future life denied to a person whose life is ended by another's act is usually much greater than that denied to a dying person whose death comes slightly more quickly due to an omission of treatment.

(4) A person, especially a patient, may still have some possibility of surviving if one omits to act, while survival is more often foreclosed by actions that lead to death.

Each of these factors—or several in combination—can make a significant moral difference in the evaluation of any particular instance of acting and omitting to act. Together they help explain why most actions leading to death are correctly considered morally worse than most omissions leading to death. Moreover, the greater stringency of the legal duties to refrain from killing than to intervene to save life reinforces people's view of which conduct is worse morally.[77]

However, the distinction between omissions leading to death and acts leading to death is not a reliable guide to their moral evaluation. In the case of medical treatment, the first and third factors are not likely to provide grounds for a distinction: family members and health professionals could be equally merciful in their intention—either in acting or omit-

[77] *See* A. D. Woozley, *Law and the Legislation of Morality*, in Arthur L. Caplan and Daniel Callahan, eds., ETHICS IN HARD TIMES, Plenum Press, New York (1981) at 143.

ting—and life may end immediately for some patients after treatment is withdrawn. Likewise, the second factor—based on the usual rule that people have fairly limited duties to save others with whom they stand in no special relation—does not apply in the medical context.[78] Health professionals have a special role-related duty to use their skills, insofar as possible, on behalf of their patients, and this duty removes any distinction between acts and omissions.

Only the final factor—turning the possibility of death into a certainty—can apply as much in medical settings as elsewhere. Indeed, this factor has particular relevance here since the element of uncertainty—whether a patient really will die if treatment is ceased—is sometimes unavoidable in the medical setting. A valid distinction may therefore arise between an act causing certain death (for example, a poisoning) and an omission that hastens or risks death (such as not amputating a gangrenous limb). But sometimes death is as certain following withdrawal of a treatment as following a particular action that is reliably expected to lead to death.

Consequently, merely determining whether what was done involved a fatal act or omission does not establish whether it was morally acceptable. Some actions that lead to death can be acceptable: very dangerous but potentially beneficial surgery or the use of hazardous doses of morphine for severe pain are examples. Some omissions that lead to death are very serious wrongs: deliberately failing to treat an ordinary patient's bacterial pneumonia or ignoring a bleeding patient's pleas for help would be totally unacceptable conduct for that patient's physician.

Not only are there difficult cases to classify as acts or omissions and difficulties in placing moral significance on the distinction, but making the distinction also presupposes an unsound conception of responsibility, namely (1) that human action is an intervention in the existing course of nature, (2) that not acting is not intervening, and (3) that people are responsible only for their interventions (or, at least, are much more responsible for deliberate interventions than for deliberate omissions). The weaknesses of this position include the ambiguous meaning of "intervention" when someone takes an action as part of a plan of nonintervention (such as writing orders not to resuscitate), the inability to define clearly the "course of nature," and the indefensibility of not holding someone responsible for states of affairs that the person could have prevented.

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[78] Ernest J. Weinrib, *The Case for a Duty to Rescue*, 90 YALE L. J. 247 (1980); Judith Jarvis Thomson, *Killing, Letting Die, and the Trolley Problem*, 59 MONIST 204 (1976). *See also* pp. 33-34 *supra* for a discussion of role-related obligations to intercede.

In sum, then, actions that lead to death are likely to be serious wrongs, while many omissions in the medical context are quite acceptable. Yet this is not a fixed moral assessment based on the mere descriptive difference between acts and omissions, but a generalization from experience that rests on such factors as whether the decision reflects the pursuit of the patient's ends and values, whether the health care providers have fulfilled their duties, and whether the risk of death has been appropriately considered.

The cause of death. Sometimes acts that lead to death seem to be more seriously wrong than omissions that likewise lead to death because the cause of death in the first instance is seen to be the act while the cause of death in an omission is regarded as the underlying disease. For example, were a physician deliberately to inject a patient with a lethal poison, the physician's action would be the cause of the patient's death. On the other hand, if an otherwise dying patient is not resuscitated in the event of cardiac arrest, or if a pneumonia or kidney failure goes untreated, the underlying disease process is said to be the cause of death. Since people ordinarily feel responsible for their own acts but not for another person's disease, this is a very comforting formulation.

The difference in this common account of causation does not actually explain the different moral assessment—rather, the account of causation *reflects* an underlying assessment of what is right or wrong under the circumstances.[79] Commonly, many factors play some causal role in a person's death. When "the cause" of a patient's death is singled out—for example, to be entered on a death certificate—the decision to designate one or more factors as "the cause(s)" depends upon the normative question at issue. Although the process begins with an empirical inquiry to identify the factors that were actually connected with a particular patient's death, both the process of narrowing to those factors that were "substantial" causes[80]

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[79] H.L.A. Hart and A.M. Honore, CAUSATION IN THE LAW, Oxford Univ. Press, Oxford, England (1959).

[80] The empirical component of causation is referred to as "actual" cause (or "cause-in-fact"). For A to be the cause of X, one might have to be able to say that "but for" (or, without the existence of) A, X would not have occurred. Where there is more than one causative agent or factor, a different test of "actual" cause must be applied, one called a "substantial factor" or "material factor" test. For instance, if Drs. A and B simultaneously give Patient C a lethal injection, neither A nor B is the "but for" cause of C's death because if A had not given the injection, C would have died anyway (from B's injection), and if B had not given the injection, C still would have died (from A's injection). Since it would be unfair for either A or B to escape liability, which would occur if the "but-for" test were applied, these other tests inquire instead whether A's conduct was a substantial (or material)

and that of deciding which ones should be held legally or morally responsible for the death involve value judgments.[81] In some situations, although one person's action is unquestionably a factual cause of another's death, holding the person responsible for the death is unfair because the death could not reasonably have been foreseen or because the person was under no obligation to prevent the death.[82]

Beyond selecting "the cause" of death from among the many factors empirically determined to have causally contributed to a patient's death, both the legal and the moral inquiry presuppose that some kinds of causal roles in a death are wrong, and then ask whether any person played any of those roles. Therefore, a determination of causation ordinarily must presuppose, and cannot itself justify, the sorts of decisions that ought to be permissible. For example, in a death following nontreatment, designating the disease as the cause not only asserts that a fatal disease process was present but also communicates acceptance of the physician's behavior in foregoing treatment. Conversely, if an otherwise healthy patient who desired treatment died from untreated pneumonia, the physician's failure to treat would be considered to have

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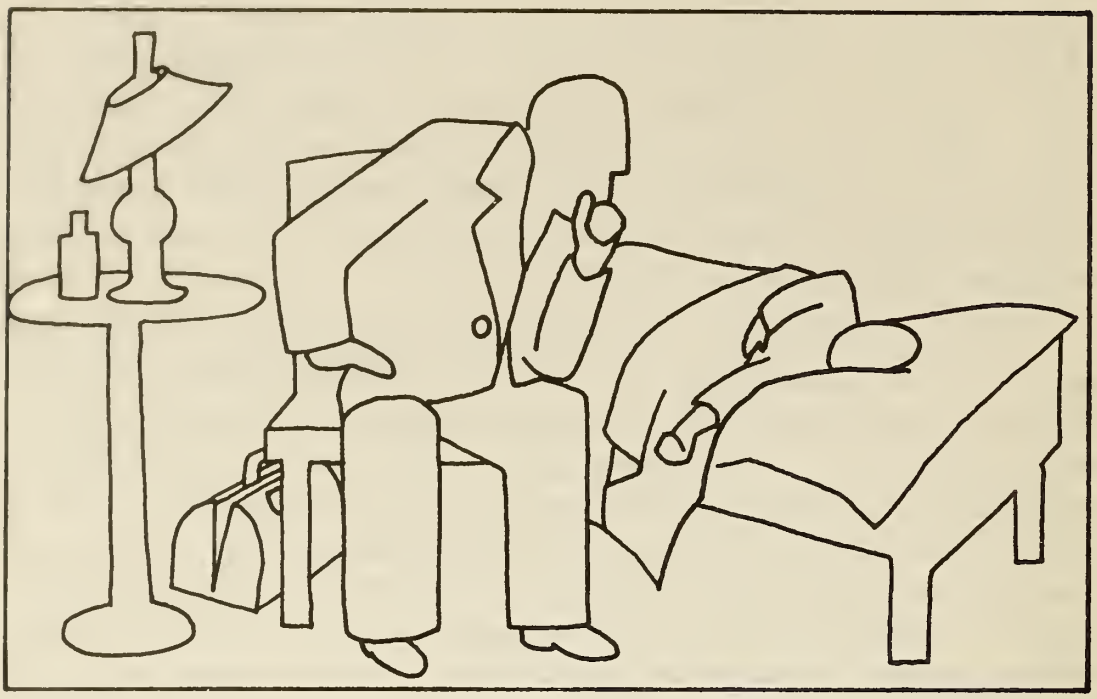
factor in bringing about C's death. If it was, A is legally culpable—and the same test is applied to B's conduct to establish B's culpability.

[81] Once it is established that the defendant's conduct has in fact been one of the causes of the plaintiff's injury, there remains the question whether the defendant should be legally responsible for what he has caused. Unlike the fact of causation, with which it is often hopelessly confused, this is essentially a problem of law....This becomes essentially a question of whether the policy of the law will extend the responsibility for the conduct to the consequences which have in fact occurred.... The term "proximate cause" is applied by the courts to those more or less undefined considerations which limit liability even where the fact of causation is clearly established.

William L. Prosser, HANDBOOK OF THE LAW OF TORTS, West Publishing Co., St. Paul, Minn. (4th ed. 1971) at 244.

[82] For instance, if in parking an automobile, a driver carelessly hits the car in front, he or she will be liable for any damage to the other car. But if the other car explodes because there was a concealed bomb in the trunk that required only a small tap to set it off, the driver may not be liable for the destruction of the car even though "but for" the driver's carelessness, the harm would not have occurred; the harm nevertheless was more substantially caused by the bomb than by the car accident and the explosion could hardly have been foreseen. And further, if several blocks away, a nurse holding a baby is startled by the explosion and drops the infant, who dies, the driver most certainly will not be liable for the infant's death despite the fact that, in the absence of the driver's carelessness, the infant would have lived. *See* Palsgraf v. Long Island R.R., 248 N.Y. 339, 162 N.E. 99 (1928) (Andrews, J., dissenting).



caused the patient's death. Although pneumonia is among the factual causes of death, one way of stating the physician's responsibility for the death is to identify the physician's omission of his or her duty to treat as the cause of death. As this example shows, the action/omission distinction does not always correspond to the usual understanding of whether the physician or the disease is the cause of death, and so the attribution of what caused a death cannot make acts morally different from omissions.

In addition, the physician's behavior is among the factual causes of a patient's death both in acting and in omitting to act. This is clear enough if a physician were to give a lethal injection—the patient would not have died at that time and in that way if the physician had not given the injection. But exactly the same is true of a physician's omission of treatment: had a physician not refrained from resuscitating or from treating a pneumonia or a kidney failure, a patient would not have died at that time and in that way. In either case, a different choice by the physician would have led to the patient living longer. To refrain from treating is justifiable in some cases—for example, if the patient does not want the treatment, is suffering, and will die very soon whatever is done. But the justification rests on these other reasons, rather than on not classifying a physician's omission as a cause of the patient's death. Thus, calling the disease the cause of death can be misleading but does reflect a sound point: that a physician who omits treatment in such a case is not morally or legally blameworthy.

The role of the distinction in public policy. The moral and legal prohibition against acting to take the life of another human being is deeply rooted in Western society and serves the laudable and extremely important value of protecting and

preserving human life. Although health care professionals and families want to do the best they can for patients, both in respecting patients' self-determination and promoting their well-being, they face troubling conflicts when doing so would involve them in conduct that might be considered as the taking of another's life.

Yet in health care, and especially with critically or terminally ill patients, it is common to make decisions that one knows risk shortening patients' lives and that sometimes turn out to do so. As a result, there is a strong motivation to interpret the actions decided upon and carried out, especially if by people other than the patient, as something other than acts of killing. Thus, the concerned parties very much want these to be regarded as cases of "allowing to die" (rather than "killing"), of "not prolonging the dying process" (instead of "hastening death"), or of "failing to stop a disease from causing death" (rather than "someone's action was the cause of death").[83] Consequently, these distinctions, while often conceptually unclear and of dubious moral importance in themselves, are useful in facilitating acceptance of sound decisions that would otherwise meet unwarranted resistance. They help people involved to understand, in ways acceptable to them, their proper roles in implementing decisions to forego life-sustaining treatment.

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[83] There would be, indeed, no defense for a doctor who went so far as to take life because in his opinion it was worthless or worse, that is an exercise of power permitted only to Juries and Judges acting through their agent the Sheriff. But to kill is one thing, and to let die is another, with a difference which, though small, is none the less real.

He Forgets Silence is Golden (Editorial), N.Y. Times, July 26, 1917 at A-10 (supporting a physician's decision not to treat a microcephalic child).

Parents of a severely compromised premature newborn have written of the kinds of reasoning that resulted from the desire of their son's doctors to be seen only as "allowing to die":

> [His doctor] spoke as if this were the moment he had been waiting for, when he could make a decision on Andrew that found its way past *commission* into *omission*....They found their loophole. Because of course I shouldn't say they "took him off" [the respirator]—they couldn't do that, since that would be immoral and illegal. They had to hope for an appropriate accident; once Andrew became accidentally detached from the respirator, and had breathed for a couple of minutes, they could declare him "off" and *omit* to put him back on while they wait for his inadequate breathing to kill him. This is the moral, legal, and "dignified" way.

Robert and Peggy Stinson, The Long Dying of Baby Andrew, Little, Brown, Boston (1983) at 343, 345.

Law, as a principal instrument of public policy in this area, has sought an accommodation that adequately protects human life while not resulting in officious overtreatment of dying patients.[84] The present general legal prohibition against deliberate, active killing, reinforced by a strong social and professional presumption in favor of sustaining life, serves as a public affirmation of the high value accorded to each human life. The law, and public policy in general, has not interpreted the termination of life-sustaining treatment, even when it requires active steps such as turning off a respirator, as falling under this general prohibition. For competent patients, the principle of self-determination is understood to include a right to refuse life-sustaining treatment, and to place a duty on providers and others to respect that right. Providers, in turn, are protected from liability when they act to aid a patient in carrying out that right. Active steps to terminate life-sustaining interventions may be permitted, indeed required, by the patient's authority to forego therapy even when such steps lead to death.[85] With adequate procedural safeguards, this right can be extended to incompetent patients through surrogates.[86]

Although there are some cases in which the acting-omitting distinction is difficult to make and although its moral importance originates in other considerations, the commonly accepted prohibition of active killing helps to produce the correct decision in the great majority of cases. Furthermore, weakening the legal prohibition to allow a deliberate taking of life in extreme circumstances would risk allowing wholly unjustified taking of life in less extreme circumstances. Such a risk would be warranted only if there were substantial evidence of serious harms to be relieved by a weakened legal protection of life, which the Commission does not find to be the case. Thus the Commission concludes that the current interpretation of the legal prohibition of active killing should be sustained.[87]

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[84] The practice of medicine raises a peculiar problem of policy for the law of homicide. It is the doctor's job to take decisions which may affect the span of human life. Therefore, it is especially important that law be neither too strict nor too lenient. If it is too strict, it will begin to make doctors criminally responsible for man's mortality; if it is too lenient it will give doctors a "license to kill." But whether the law does steer a middle course between these two extremes, or, indeed, is capable of doing so without greatly distorting the general principles of the criminal law, is a different matter.

Helen Beynon, *Doctors as Murderers*, 1982 CRIM. L. REV. 17, 17-18.

[85] *See, e.g.*, State v. Perlmutter, 379 So.2d 359 (Fla. 1980); *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 671, *cert. denied*, 429 U.S. 922 (1976).

[86] *See* Chapter Four *infra*.

[87] Evaluating the policy role of the acting/omitting distinction in

One serious consequence of maintaining the legal prohibition against direct killing of terminally ill patients could be the prolongation of suffering. In the final stages of some diseases, such as cancer, patients may undergo unbearable suffering that only ends with death. Some have claimed that sometimes the only way to improve such patients' lot is to actively and intentionally end their lives.[88] If such steps are forbidden, physicians and family might be forced to deny these patients the relief they seek and to prolong their agony pointlessly.

If this were a common consequence of a policy prohibiting all active termination of human life, it should force a reevaluation of maintaining the prohibition. Rarely, however, does such suffering persist when there is adequate use of pain-relieving drugs and procedures.[89] Health care professionals ought to realize that they are already authorized and obligated to use such means with a patient's or surrogate's consent, even if an earlier death is likely to result. The Commission endorses allowing physicians and patients to select treatments known to risk death in order to relieve suffering as well as to pursue a return to health.

Policies prohibiting direct killing may also conflict with the important value of patient self-determination. This conflict will arise when deliberate actions intended to cause death have been freely chosen by an informed and competent patient as the necessary or preferred means of carrying out his or her wishes, but the patient is unable to kill him or herself unaided, or others prevent the patient from doing so. The frequency with which this conflict occurs is not known, although it is probably rare. The Commission finds this limitation on individual self-determination to be an acceptable cost of securing the general protection of human life afforded by the prohibition of direct killing.

Withholding Versus Withdrawing Treatment. A variation on the action/omission distinction sometimes troubles physicians who allow competent patients to refuse a life-sustaining treatment but who are uncomfortable about stopping a treatment that has already been started because doing so seems to

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regulating behavior requires balancing its positive value as a safeguard that protects human life against its negative consequences of contributing to some undesirable decisions. The law has used conceptually unclear reinterpretations to remove most foregoings of life-sustaining treatment from the behaviors that count as "acting" or "wrongful killing." These are important in reducing the frequency of morally undesirable decisions that might otherwise arise.

[88] George Fletcher, *Prolonging Life*, 42 WASH. L. REV. 999 (1967); Robertson, *supra* note 64, at 20-22; Christian Barnard, GOOD LIFE/GOOD DEATH, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1980) at 110-17.

[89] *See* pp. 19-20 *supra* and Appendix B, pp. 275-97 *infra*.

them to constitute killing the patient. By contrast, not starting a therapy seems acceptable, supposedly because it involves an omission rather than an action.[90]

Although the nature of the distinction between withholding and withdrawing seems clear enough initially, cases that obscure it abound. If a patient is on a respirator, disconnecting would count as stopping. But if the patient is on a respirator and the power fails, does failing to use a manual bellows mechanism count as "stopping" a therapy (artificial respiration) or "not starting" a therapy (manually generated respiration)?[91] Many therapies in medicine require repeated applications of an intervention. Does failing to continue to reapply the intervention count as "stopping" (the series of treatments) or as "not starting" (the next element in the series)? Even when a clear distinction can be drawn between withdrawing and withholding, insofar as the distinction is merely an instance of the acting-omitting distinction it lacks moral significance.[92]

Other considerations may be involved here, however. Even though health care professionals may not be obligated to initiate a therapy with a particular patient, its initiation may create expectations on the part of the patient and others. In some instances these expectations may lead the health care provider to feel obliged not to stop a therapy that initially could have been foregone.[93] (Similarly, a physician, who is under no obligation to accept any particular person as a patient, may not abandon a patient once a physician-patient relationship has been established.[94])

This observation does not actually argue that stopping a treatment is in itself any more serious than not starting it. What it claims is that *if* additional obligations to treat have arisen from any expectations created once a treatment has been initiated, then stopping, because it breaches those obligations, is worse than not starting. The expectations, and

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[90] "By not starting a 'routine IV' I am not committed to that modality of therapy. It is easier *not* to start daily intravenous parenteral fluids than to stop them, once begun—just as it is easier not to turn on the respiratory assistance machine than to turn the switch off, once started." Louis Shattluck Baer, *Nontreatment of Some Severe Strokes*, 4 Annals Neurol. 381, 382 (Oct. 1978).

[91] *See, e.g.*, Alan J. Weisbard, *On the Bioethics of Jewish Law: The Case of Karen Quinlan*, 14 Israel L. Rev. 337, 346 (1979).

[92] *See* pp. 66-68 *supra*.

[93] *See, e.g.*, George J. Annas, The Rights of Hospital Patients, Avon Books, New York (1975) at 92, 95-96; Albert R. Jonsen, Mark Siegler, and William J. Winslade, Clinical Ethics, Macmillan Pub. Co., New York (1982) at 100.

[94] *See* Jon R. Waltz and Fred E. Inbau, Medical Jurisprudence, Macmillan Pub. Co., New York (1971) at 142-51; Angela R. Holder, Medical Malpractice Law, John Wiley & Sons, New York (1975) at 375.

the resultant obligation to continue, create whatever moral difference arises. The definition of the professional-patient relationship and the creation of expectations that care will be continued occur in complex ways—from professional codes, patterns of practice, legal decisions, and physician-patient communications. A particular physician faced with stopping or not starting therapy with a particular patient may have to accept a relationship and expectations that are at least partly givens.

Discussions between a physician and competent patient, however, allow redefinition of their relationship and alteration of their expectations and thus of any resulting obligations. For example, a physician and patient could agree to a time-limited trial of a particular intervention, with an understanding that unless the therapy achieved certain goals it should be stopped. Moreover, these relationships and expectations, with their resultant obligations, need not be treated as fixed when public policy is being made but can be redefined where appropriate. Of course, most withdrawals of treatment involve explicit decisions while withholdings are commonly implicit and not clearly discussed (although, in conformity with the Commission's recommendations, they should be discussed, except in emergency situations).[95] Although this may make the withdrawal of treatment more anguishing, or even more likely to precipitate external review, it does not make it morally different.

Adopting the opposite view—that treatment, once started, cannot be stopped, or that stopping requires much greater justification than not starting—is likely to have serious adverse consequences. Treatment might be continued for longer than is optimal for the patient, even to the point where it is causing positive harm with little or no compensating benefit.[96] An even more troubling wrong occurs when a treatment that might save life or improve health is not started because the health care personnel are afraid that they will find it very difficult to stop the treatment if, as is fairly likely, it proves to be of little benefit and greatly burdens the patient.[97] The Commission

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[95] *See* p. 51 *supra*.

[96] Such "overtreatment" has resulted in the filing of a lawsuit by a deceased patient's family. Leach v. Shapiro, Civ. Action C-81-2559A, Summit County, Oh. (1982); Leach v. Akron General Medical Center, 426 N.E.2d 809 (Ohio Com. Pl. 1980).

[97] Another problem is whether a distinction should be made between causing someone to die by commission of a positive act and allowing someone to die through inaction, i.e., withholding treatment. Whether one physician would be held criminally liable for "pulling the plug" when another would not be liable for failing to start the initial treatment is unclear. Certainly, however, to maintain that there is a difference in the degree of culpability may have the undesirable effect of

received testimony, for example, that sometimes the view that a therapy that has been started could not be stopped had unduly raised the threshold for initiating some forms of vigorous therapy for newborns.[98] In cases of extremely low birth weight or severe spina bifida, for example, highly aggressive treatment may significantly benefit a small proportion of the infants treated while it prolongs the survival of a great number of newborns for whom treatment turns out to be futile. Fear of being unable to stop treatment in the latter cases—no matter how compelling the reason to stop—can lead to failure to treat the entire group, including the few infants who would have benefited.

Ironically, if there is any call to draw a moral distinction between withholding and withdrawing, it generally cuts the opposite way from the usual formulation: greater justification ought to be required to withhold than to withdraw treatment. Whether a particular treatment will have positive effects is often highly uncertain before the therapy has been tried. If a trial of therapy makes clear that it is not helpful to the patient, this is actual evidence (rather than mere surmise) to support stopping because the therapeutic benefit that earlier was a possibility has been found to be clearly unobtainable.[99]

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promoting nontreatment over treatment.

Comment, *Medico-Legal Implications of "Orders Not to Resuscitate,"* 31 CATH. U.L. REV. 515, 519 n.12 (1982) (citation omitted).

[98] Testimony of Dr. John Freeman, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 124-25.

> [99] A decision to stop "extraordinary" life-sustaining treatments requires no greater and in fact the same moral warrant as a decision not to begin to use them....Since a trial treatment is often a part of diagnosis of a patient's condition, one might expect there to be greater reluctance on the part of physicians in not starting than in stopping extraordinary efforts to save life. As I understand them, physicians often have the contrary difficulty....The reasons for these variations are probably psychological rather than rational.

Paul Ramsey, THE PATIENT AS PERSON, Yale Univ. Press, New Haven, Conn. (1970) at 121-22. *See also* James F. Childress, PRIORITIES IN BIOMEDICAL ETHICS, Westminister Press, Philadelphia (1981) at 123, n.10.

Commenting on Judge Robert Meade's ruling in the Brother Fox case that "it is important that the law not create a disincentive to the fullest treatment of patients by making it impossible for them in at least some extreme circumstances to choose to end treatment which has proven unsuccessful," John Paris noted: "With that legal support for the standard that once the patient has been given the benefit of all known procedures and these prove unsuccessful in restoring health, they need not be uselessly continued. It is to be hoped that the legal

Behind the withholding/withdrawing distinction lies the more general acting/omitting distinction in one of its least defensible forms. Given that the Commission considers as unwarranted the view that steps leading to death are always more serious when they involve an act rather than an omission, it also rejects the view that stopping a treatment ("an act") is morally more serious than not starting it ("an omission") could be.

Little if any legal significance attaches to the distinction between withholding and withdrawing. Nothing in law—certainly not in the context of the doctor-patient relationship—makes stopping treatment a more serious legal issue than not starting treatment. In fact, not starting treatment that *might* be in a patient's interests is more likely to be held a civil or criminal wrong than stopping the same treatment when it has proved unavailing.

As is the case with the distinction between acting and omitting, many other factors of moral importance may differentiate the appropriateness of a particular decision not to start from one to stop. Yet whatever considerations justify not starting should justify stopping as well. Thus the Commission concludes that neither law nor public policy should mark a difference in moral seriousness between stopping and not starting treatment.

Intended Versus Unintended But Foreseeable Consequences. Since there are sound moral and policy reasons to prohibit such active steps as administering strychnine or using a gun to kill a terminally ill patient, the question arises as to whether physicians should be able to administer a symptom-relieving drug—such as a pain-killer—knowing that the drug may cause or accelerate the patient's death, even though death is not an outcome the physician seeks. The usual answer to this question—that the prohibition against active killing does not bar the use of appropriate medical treatment, such as morphine for pain[100]—is often said to rest on a distinction between the

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recognition of that moral reality will help overcome physician timidity in similar cases." John J. Paris, *Brother Fox: The Courts and Death with Dignity*, 143 AMERICA 282, 284 (1980).

[100] In this situation, death occurs because patients in the terminal stages of diseases like cancer sometimes undergo suffering so great that it can only be relieved by doses of morphine that are so large as to induce respiratory depression or to predispose the patient to pneumonia, which may result in an earlier death. The Commission notes that such an occurrence should not be termed an "overdose," with its implications of excessive dosage, since the use of the correct dose of morphine to relieve suffering is really an acceptable practice. On the other hand, relief of pain can extend life: "the relief and comfort given an aged patient often affects the prolongation of life if only by restoring the willingness to live." Alfred Worcester, THE CARE

goals physicians seek to achieve or the means they use, on the one hand, and the unintended but foreseeable[101] consequences of their actions on the other.[102]

One problem with assigning moral significance to the traditional distinction is that it is sometimes difficult to determine whether a particular aspect of a course of action ought to be considered to be intended, because it is an inseparable part of the "means" by which the course of action is achieved, or whether it is merely an unintended but foreseeable consequence. In medicine, and especially in the treatment of the critically or terminally ill, many of the courses that might be followed entail a significant risk, sometimes approaching a certainty, of shortening a patient's life. For example, in order to avoid additional suffering or disability, or perhaps to spare loved ones extreme financial or emotional costs, a patient may elect not to have a potentially life-extending operation. Risking earlier death might plausibly be construed as the intended means to these other ends, or as an unintended and "merely foreseeable" consequence. Since there seems to be no generally accepted, principled basis for making the distinction, there is substantial potential for unclear or contested determinations.

Even in cases in which the distinction is clear, however, health care professionals cannot use it to justify a failure to consider all the consequences of their choices.[103] By choosing a course of action, a person knowingly brings about certain effects; other effects could have been caused by deciding differently. The law reflects this moral view and holds people to be equally responsible for all the reasonably foreseeable results of their actions and not just for those results that they acknowledge having intended to achieve.[104] Nevertheless, although medication is commonly used to relieve the suffering of dying patients (even when it causes or risks causing death), physicians are not held to have violated the law. How can this

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OF THE AGED, THE DYING AND THE DEAD, Charles C. Thomas, Springfield, Ill. (1935) *reprinted by* Arno Press, Inc., New York (1977) at 6.

[101] The customary use of "foreseeable" is for those things that would be predicted as possible outcomes by a person exercising reasonable foresight; it is not limited to consequences that are certain or nearly certain to occur.

[102] The moral importance of this distinction is defended in Charles Fried, RIGHT AND WRONG, Harvard Univ. Press, Cambridge, Mass. (1978) at 7-53. *But see* Alan Donagan, THE THEORY OF MORALITY, Univ. of Chicago Press, Chicago (1977) at 112-71.

[103] Donagan, *supra* note 102, at 164; R.G. Frey, *Some Aspects to the Doctrine of Double Effect*, 5 CANADIAN J. PHIL. 259 (1975); Philippa Foot, *The Problem of Abortion and the Doctrine of the Double Effect*, 5 OXFORD REV. 5 (1967).

[104] RESTATEMENT (SECOND) OF TORTS, American Law Institute Publishers, St. Paul, Minn. (1965) at §§ 289-91.

failure to prosecute be explained, since it does not rest on an explicit waiver of the usual legal rule?

The explanation lies in the importance of defining physicians' responsibilities regarding these choices and of developing an accepted and well-regulated social role that allows the choices to be made with due care. The search for medical treatments that will benefit a patient often involves risk, sometimes great risk, for the patient: for example, some surgery still carries a sizable risk of mortality, as does much of cancer therapy. Furthermore, seeking to cure disease and to prolong life is only a part of the physician's traditional role in caring for patients; another important part is to comfort patients and relieve their suffering.[105] Sometimes these goals conflict, and a physician and patient (or patient's surrogate) have the authority to decide which goal has priority. Medicine's role in relieving suffering is especially important when a patient is going to die soon, since the suffering of such a patient is not an unavoidable aspect of treatment that might restore health, as it might be for a patient with a curable condition.

Consequently, the use of pain-relieving medications is distinguished from the use of poisons, though both may result in death, and society places the former into the category of acceptable treatment while continuing the traditional prohibition against the latter.[106] Indeed, in the Commission's view it is not only possible but desirable to draw this distinction. If physicians (and other health professionals) became the dispensers of "treatments" that could only be understood as deliberate killing of patients, patients' trust in them might be seriously undermined.[107] And irreparable damage could be done to health care professionals' self-image and to their ability to devote themselves wholeheartedly to the often arduous task of treating gravely ill patients. Moreover, whether or not one believes there are some instances in which giving a poison might be morally permissible, the Commission consid-

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[105] Judicial Council, CURRENT OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION, American Medical Association, Chicago (1982) at 9, *reprinted in* Appendix C, pp. 299-300 *infra*.

[106] "Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course." *Selections from the Hippocratic Corpus: Oath*, in Stanley Joel Reiser, Arthur J. Dyck, and William J. Curran, eds., ETHICS IN MEDICINE, MIT Press, Cambridge, Mass. (1977) at 5.

[107] "Euthanasia would threaten the patient-physician relationship; confidence might give way to suspicion....Can the physician, historic battler for life, become an affirmative agent of death without jeopardizing the trust of his dependents?" David W. Louisell, *Euthanasia and Biathanasia: On Dying and Killing*, 40 LINACRE Q. 234, 243 (1973).

ers that the obvious potential for abuse of a public, legal policy condoning such action argues strongly against it.[108]

For the use of morphine or other pain-relieving medication that can lead to death to be socially and legally acceptable, physicians must act within the socially defined bounds of their role.[109] This means that they are not only proceeding with the necessary agreement of the patient (or surrogate) and in a professionally skillful fashion (for example, by not taking a step that is riskier than necessary), but that there are sufficiently weighty reasons to run the risk of the patient dying.[110] For example, were a person experiencing great pain from a condition that will be cured in a few days, use of morphine at doses that would probably lead to death by inducing respiratory depression would usually be unacceptable. On the other hand, for a patient in great pain—especially from a condition that has proved to be untreatable and that is expected to be rapidly fatal—morphine can be both morally and legally acceptable if pain relief cannot be achieved by less risky means.

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[108] Yale Kamisar, *Some Non-Religious Views Against Proposed 'Mercy-Killing' Legislation*, 42 MINN. L. REV. 969 (1958); Beauchamp, *supra note 73; John C. Fletcher, Is Euthanasia Ever Justifiable?*, in Peter H. Wiernik, ed., CONTROVERSIES IN ONCOLOGY, John Wiley & Sons, Inc., New York (1982) at 297.

[109] *See* Dennis Horan, *Euthanasia and Brain Death*, 35 ANNALS N.Y. ACAD. SCI. 363, 374 (1978). *Cf.* Tamar Lewin, *Execution by Injection: A Dilemma for Prison Doctors*, N.Y. TIMES, Dec. 12, 1982, at E-20; Norman St. John-Stevas, LIFE, DEATH AND THE LAW, World Publishing Co., New York (1961) at 276-77.

[110] This consideration plays a prominent part in what is known in Catholic medical ethics as the "doctrine of double effect." This doctrine, which is designed to provide moral guidance for an action that could have at least one bad and one good effect, holds that such an action is permissible if it satisfies these four conditions: (1) the act itself must be morally good or neutral (for example, administering a pain-killer); (2) only the good consequences of the action must be intended (relief of the patient's suffering); (3) the good effect must not be produced by means of the evil effect (the relief of suffering must not be produced by the patient's death); and (4) there must be some weighty reason for permitting the evil (the relief of great suffering, which can only be achieved through a high risk of death). The Commission makes use of many of the moral considerations found in this doctrine, but endorses the conclusion that people are equally responsible for all of the foreseeable effects of their actions, thereby having no need for a policy that separates "means" from "merely foreseen consequences." *See, e.g.*, William E. May, *Double Effect*, in 1 ENCYCLOPEDIA OF BIOETHICS, *supra* note 73, at 316; Joseph T. Mangan, S.J., *An Historical Analysis of the Principle of Double Effect*, 10 THEOLOGICAL STUD. 4 (1949); Donagan, *supra* note 102; Richard A. McCormick, S.J., AMBIGUITY IN MORAL CHOICE, Marquette Univ. Press, Milwaukee, Wisc. (1973); J.M. Boyle, *Toward Understanding the Principle of Double Effect*, 90 ETHICS 527 (1980).

President's Commission for the Study of Ethical Problems
in Medicine and Biomedical and Behavioral Research
Suite 555, 2000 K Street, N.W., Washington, DC 20006 (~~202) 653-8051~~

March 21, 1983

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

On behalf of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, I am pleased to transmit our Report on Deciding to Forego Life-Sustaining Treatment. This subject was not part of our original legislative mandate but was added as a natural outgrowth of our studies on informed consent, the "definition" of death, and access to health care and because it seemed to us to involve some of the most important and troubling ethical and legal questions in modern medicine.

Although our study has done nothing to decrease our estimation of the importance of this subject to physicians, patients, and their families, we have concluded that the cases that involve true ethical difficulties are many fewer than commonly believed and that the perception of difficulties occurs primarily because of misunderstandings about the dictates of law and ethics. Neither criminal nor civil law precludes health care practitioners or their patients and relatives from reaching ethically and medically appropriate decisions about when to engage in or to forego efforts to sustain the lives of dying patients.

Applying the findings of our earlier study on informed consent, we have concluded that the authority of competent, informed patients to decide about their health care encompasses the decision to forego treatment and allow death to occur. We note, however, that all patients, including those who reject various forms of life-support, should receive other appropriate medical care to preserve their dignity and minimize suffering to the greatest extent possible.

When patients are incompetent to make their own decisions, others must act on their behalf. The Commission found that existing legal procedures can be adapted for the purpose of allowing people while competent to designate someone to act in their stead and to express their wishes about treatment. When it is not possible to know what a particular patient would have chosen--as, for example, with seriously ill infants--those who make the choices should attempt to serve the patient's best interests, judged from the patient's vantage point. To ensure that the interests of incompetent patients are protected, the Commission urges that health care institutions develop and utilize methods of internal review that will permit all relevant issues to be explored and all opinions to be heard and that will improve communication among the full treatment team and patients' family members.

We are grateful for the opportunity to contribute to improving public understanding of this vital topic.

Respectfully,

Morris B. Abram
Chairman

President's Commission for the Study of Ethical Problems
in Medicine and Biomedical and Behavioral Research
Suite 555, 2000 K Street, N.W., Washington, DC 20006 (202) 653-8051

March 21, 1983

The Honorable George Bush
President
United States Senate
Washington, D.C. 20510

Dear Mr. President:

On behalf of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, I am pleased to transmit our Report on Deciding to Forego Life-Sustaining Treatment. This subject was not part of our original legislative mandate but was added as a natural outgrowth of our studies on informed consent, the "definition" of death, and access to health care and because it seemed to us to involve some of the most important and troubling ethical and legal questions in modern medicine.

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March 21, 1983

The Honorable Thomas P. O'Neill, Jr.
Speaker
U. S. House of Representatives
Washington, D.C. 20515

Dear Mr. Speaker:

On behalf of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, I am pleased to transmit our Report on Deciding to Forego Life-Sustaining Treatment. This subject was not part of our original legislative mandate but was added as a natural outgrowth of our studies on informed consent, the "definition" of death, and access to health care and because it seemed to us to involve some of the most important and troubling ethical and legal questions in modern medicine.

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Morris B. Abram
Chairman

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Introduction and Summary

Americans seem to be increasingly concerned with decisions about death and dying. Why is a subject once thought taboo now so frequently aired by the popular media, debated in academic forums and professional societies, and litigated in well-publicized court cases?

Perhaps it is because death is less of a private matter than it once was. Today, dying more often than not occurs under medical supervision, usually in a hospital or nursing home. Actions that take place in such settings involve more people, and the resolution of disagreements among them is more likely to require formal rules and means of adjudication. Moreover, patients dying in health care institutions today typically have fewer of the sources of nonmedical support, such as family and church, that once helped people in their final days.

Also important, no doubt, are the biomedical developments of the past several decades. Without removing the sense of loss, finality, and mystery that have always accompanied death, these new developments have made death more a matter of deliberate decision. For almost any life-threatening condition, some intervention can now delay the moment of death. Frequent dramatic breakthroughs—insulin, antibiotics, resuscitation, chemotherapy, kidney dialysis, and organ transplantation, to name but a few—have made it possible to retard and even to reverse many conditions that were until recently regarded as fatal. Matters once the province of fate have now become a matter of human choice, a development that has profound ethical and legal implications.

Moreover, medical technology often renders patients less able to communicate or to direct the course of treatment. Even for mentally competent patients, other people must usually assist in making treatment decisions or at least acquiesce in carrying them out. Consequently, in recent years there has

been a continuing clarification of the rights, duties, and liabilities of all concerned, a process in which professionals, ethical and legal commentators, and—with increasing frequency—the courts and legislatures have been involved.

Thus, the Commission found this an appropriate time to reexamine the way decisions are and ought to be made about whether or not to forego life-sustaining treatment.[1] For example, may a patient's withdrawal from treatment ever be forbidden? Should physicians acquiesce in patients' wishes regarding therapy? Should they offer patients the option to forego life-sustaining therapy? Does it make any difference if the treatment has already been started, or involves mechanical systems of life support, or is very costly?

Summary of Conclusions

Building on a central conclusion of its report on informed consent[2]—that decisions about health care ultimately rest with competent patients—the Commission in this Report examines the situations in which a patient's choice to forego life-sustaining therapy may be limited on moral or legal grounds. In addition to providing clarification of the issues, the Report suggests appropriate procedures for decisions regarding both competent and incompetent patients and scrutinizes the role of various public and private bodies in shaping and regulating the process.

These aims are the only ones that this Commission believes to be within the scope of its role. The Report does not judge any particular future case nor provide a guidebook of the morally correct choice for patients and health care providers who are facing such a decision. Rather, the Commission intends to illuminate the strengths and weaknesses of various considerations and various instruments of social policy. Clarifying the relevant considerations and prohibitions may help decisionmakers, but it may also force them to confront painful realities more directly. The Commission hopes that this Report

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[1] "To forego life-sustaining treatment" means to do without a medical intervention that would be expected to extend the length of the patient's life. "Foregoing" includes both the non-initiation of a treatment and the discontinuation of an ongoing treatment. The terms "therapy" and "medical intervention" are used interchangeably with "treatment" in this Report. When a patient's underlying condition is incurable and will probably soon be fatal, "therapy" or "treatment" may not seem entirely apt, because these terms usually imply a curative intervention. Nevertheless, the terms are used here both because no better ones are available and because they are commonly used.

[2] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, MAKING HEALTH CARE DECISIONS, U.S. Government Printing Office, Washington (1982).

will help improve the process, but recognizes that an improved process will not necessarily make decisions easier.

The Report addresses a broad range of problems and patient situations. Serious questions about whether life should be sustained through a particular treatment usually arise when a patient is suffering from a known disease likely to prove fatal in the near future rather than in an unanticipated emergency (where any decisionmaking would necessarily have to be truncated). Life-sustaining treatment, as used here, encompasses all health care interventions that have the effect of increasing the life span of the patient. Although the term includes respirators, kidney machines, and all the paraphernalia of modern medicine, it also includes home physical therapy, nursing support for activities of daily living, and special feeding procedures, provided that one of the effects of the treatment is to prolong a patient's life.

The issues addressed in this Report are complex and their resolution depends not only on the context of particular decisions but also on their relationship to other values and principles. Thus, it is exceptionally difficult to summarize the Commission's conclusions on this subject. The synopsis provided here should be read in the context of the reasoning, elaboration, and qualifications provided in the chapters that follow.

(1) The voluntary choice of a competent and informed patient should determine whether or not life-sustaining therapy will be undertaken, just as such choices provide the basis for other decisions about medical treatment. Health care institutions and professionals should try to enhance patients' abilities to make decisions on their own behalf and to promote understanding of the available treatment options.

(2) Health care professionals serve patients best by maintaining a presumption in favor of sustaining life, while recognizing that competent patients are entitled to choose to forego any treatments, including those that sustain life.

(3) As in medical decisionmaking generally, some constraints on patients' decisions are justified.

- Health care professionals or institutions may decline to provide a particular option because that choice would violate their conscience or professional judgment, though in doing so they may not abandon a patient.
- Health care institutions may justifiably restrict the availability of certain options in order to use limited resources more effectively or to enhance equity in allocating them.
- Society may decide to limit the availability of certain options for care in order to advance equity or the general welfare, but such policies should not be

applied initially nor especially forcefully to medical options that could sustain life.

- Information about the existence and justification of any of these constraints must be available to patients or their surrogates.

(4) Governmental agencies, institutional providers of care, individual practitioners, and the general public should try to improve the medically beneficial options that are available to dying patients. Specific attention should be paid to making respectful, responsive, and competent care available for people who choose to forego life-sustaining therapy or for whom no such therapies are available.

(5) Several distinctions are employed by health care professionals and others in deliberating about whether a choice that leads to an earlier death would be acceptable or unacceptable in a particular case. Unfortunately, people often treat these distinctions—between acts and omissions that cause death, between withholding and withdrawing care, between an intended death and one that is merely foreseeable, and between ordinary and extraordinary treatment—as though applying them decided the issue, which it does not. Although there is a danger that relying on such labels will take the place of analysis, these distinctions can still be helpful if attention is directed to the reasoning behind them, such as the degree to which a patient is benefited or burdened by a treatment.

(6) Achieving medically and morally appropriate decisions does not require changes in statutes concerning homicide or wrongful death, given appropriate prosecutorial discretion and judicial interpretation.

(7) Primary responsibility for ensuring that morally justified processes of decisionmaking are followed lies with physicians. Health care institutions also have a responsibility to ensure that there are appropriate procedures to enhance patients' competence, to provide for designation of surrogates, to guarantee that patients are adequately informed, to overcome the influence of dominant institutional biases, to provide review of decisionmaking, and to refer cases to the courts appropriately. The Commission is not recommending that hospitals and other institutions take over decisions about patient care; there is no substitute for the dedication, compassion, and professional judgment of physicians. Nevertheless, institutions need to develop policies because their decisions have profound effects on patient outcomes, because society looks to these institutions to ensure the means necessary to preserve both health and the value of self-determination, and because they are conveniently situated to provide efficient, confidential, and rapid supervision and review of decisionmaking.

Incompetent Patients Generally

(8) Physicians who make initial assessments of patients' competence and others who review these assessments should be responsible for judging whether a particular patient's decisionmaking abilities are sufficient to meet the demands of the specific decision at hand.

(9) To protect the interests of patients who have insufficient capacity to make particular decisions and to ensure their well-being and self-determination:

- An appropriate surrogate, ordinarily a family member, should be named to make decisions for such patients. The decisions of surrogates should, when possible, attempt to replicate the ones that the patient would make if capable of doing so. When lack of evidence about the patient's wishes precludes this, decisions by surrogates should seek to protect the patient's best interests.[3] Because such decisions are not instances of self-choice by the patient, the range of acceptable decisions by surrogates is sometimes not as broad as it would be for patients making decisions for themselves.
- The medical staff, along with the trustees and administrators of health care institutions, should explore and evaluate various formal and informal administrative arrangements for review and consultation, such as "ethics committees," particularly for decisions that have life-or-death consequences for incompetent patients.
- State courts and legislatures should consider making provision for advance directives through which people designate others to make health care decisions on their behalf and/or give instructions about their care. Such advance directives provide a means of preserving some self-determination for patients who may lose their decisionmaking capacity. Durable powers of attorney are preferable to "living wills" since they are more generally applicable and provide a better vehicle for patients to exercise self-determination, though experience with both is limited.
- Health care professionals and institutions should adopt clear, explicit, and publicly available policies regarding how and by whom decisions are to be made

[3] "Decisionmaking guided by the best interests standard requires a surrogate to do what, from an objective standpoint, appears to promote a patient's good without reference to the patient's actual or supposed preferences." MAKING HEALTH CARE DECISIONS, *supra* note 2, at 179. *See also* pp. 131-36 *infra*.

for patients who lack adequate decisionmaking capacity.

- Families, health care institutions, and professionals should work together to make decisions for patients who lack decisionmaking capacity. Recourse to the courts should be reserved for the occasions when adjudication is clearly required by state law or when concerned parties have disagreements that they cannot resolve over matters of substantial import. Courts and legislatures should be cautious about requiring judicial review of routine health care decisions for patients with inadequate decisionmaking capacity.

Patients with Permanent Loss of Consciousness

(10) Current understanding of brain functions allows a reliable diagnosis of permanent loss of consciousness for some patients. Whether or not life-sustaining treatment is given is of much less importance to such patients than to others.

(11) The decisions of patients' families should determine what sort of medical care permanently unconscious patients receive. Other than requiring appropriate decisionmaking procedures for these patients, the law does not and should not require any particular therapies to be applied or continued, with the exception of basic nursing care that is needed to ensure dignified and respectful treatment of the patient.

(12) Access to costly care for patients who have permanently lost consciousness may justifiably be restricted on the basis of resource use in two ways: by a physician or institution that otherwise would have to deny significantly beneficial care to another specific patient, or by legitimate mechanisms of policy formulation and application if and only if the provision of certain kinds of care to these patients were clearly causing serious inequities in the use of community resources.

Seriously Ill Newborns

(13) Parents should be the surrogates for a seriously ill newborn unless they are disqualified by decisionmaking incapacity, an unresolvable disagreement between them, or their choice of a course of action that is clearly against the infant's best interests.

(14) Therapies expected to be futile for a seriously ill newborn need not be provided; parents, health care professonals and institutions, and reimbursement sources, however, should ensure the infant's comfort.

(15) Within constraints of equity and availability, infants should receive all therapies that are clearly beneficial to them. For example, an otherwise healthy Down Syndrome child whose life is threatened by a surgically correctable complication should receive the surgery because he or she would clearly benefit from it.

- The concept of benefit necessarily makes reference to the context of the infant's present and future treatment, taking into account such matters as the level of biomedical knowledge and technology and the availability of services necessary for the child's treatment.
- The dependence of benefit upon context underlines society's special obligation to provide necessary services for handicapped children and their families, which rests on the special ethical duties owed to newborns with undeserved disadvantages and on the general ethical duty of the community to ensure equitable access for all persons to an adequate level of health care.[4]

(16) Decisionmakers should have access to the most accurate and up-to-date information as they consider individual cases.

- Physicians should obtain appropriate consultations and referrals.
- The significance of the diagnoses and the prognoses under each treatment option must be conveyed to the parents (or other surrogates).

(17) The medical staff, administrators, and trustees of each institution that provides care to seriously ill newborns should take the responsibility for ensuring good decisionmaking practices. Accrediting bodies may want to require that institutions have appropriate policies in this area.

- An institution should have clear and explicit policies that require prospective or retrospective review of decisions when life-sustaining treatment for an infant might be foregone or when parents and providers disagree about the correct decision for an infant. Certain categories of clearly futile therapies could be explicitly excluded from review.
- The best interests of an infant should be pursued when those interests are clear.
- The policies should allow for the exercise of parental discretion when a child's interests are ambiguous.
- Decisions should be referred to public agencies (including courts) for review when necessary to determine whether parents should be disqualified as decisionmakers and, if so, who should decide the course of

[4] "A determination of this [adequate] level will take into account the value of various types of health care in relation to each other as well as the value of health care in relation to other important goods for which societal resources are needed." President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Securing Access to Health Care, U.S. Government Printing Office, Washington (1983) at 4-5.

treatment that would be in the best interests of their child.

(18) The legal system has various—though limited—roles in ensuring that seriously ill infants receive the correct care.

- Civil courts are ultimately the appropriate decision-makers concerning the disqualification of parents as surrogates and the designation of surrogates to serve in their stead.
- Special statutes requiring providers to bring such cases to the attention of civil authorities do not seem warranted, since state laws already require providers to report cases of child abuse or neglect to social service agencies; nevertheless, educating providers about their responsibilities is important.
- Although criminal penalties should be available to punish serious errors, the ability of the criminal law to ensure good decisionmaking in individual cases is limited.
- Governmental agencies that reimburse for health care may insist that institutions have policies and procedures regarding decisionmaking, but using financial sanctions against institutions to punish an "incorrect" decision in a particular case is likely to be ineffective and to lead to excessively detailed regulations that would involve government reimbursement officials in bedside decisionmaking. Furthermore, such sanctions could actually penalize other patients and providers in an unjust way.

Cardiopulmonary Resuscitation

(19) A presumption favoring resuscitation of hospitalized patients in the event of unexpected cardiac arrest is justified.

(20) A competent and informed patient or an incompetent patient's surrogate is entitled to decide with the attending physician that an order against resuscitation should be written in the chart. When cardiac arrest is likely, a patient (or a surrogate) should usually be informed and offered the chance specifically to decide for or against resuscitation.

(21) Physicians have a duty to assess for each hospitalized patient whether resuscitation is likely, on balance, to benefit the patient, to fail to benefit, or to have uncertain effect.

- When a patient will not benefit from resuscitation, a decision not to resuscitate, with the consent of the patient or surrogate, is justified.
- When a physician's assessment conflicts with a competent patient's decision, further discussion and consultation are appropriate; ultimately the physician must follow the patient's decision or transfer responsibility for that patient to another physician.

- When a physician's assessment conflicts with that of an incompetent patient's surrogate, further discussion, consultation, review by an institutional committee, and, if necessary, judicial review should be sought.

(22) To protect the interests of patients and their families, health care institutions should have explicit policies and procedures governing orders not to resuscitate, and accrediting bodies should require such policies.

- Such policies should require that orders not to resuscitate be in written form and that they delineate who has the authority both to write such orders and to stop a resuscitation effort in progress.
- Federal agencies responsible for the direct provision of patient care (such as the Veterans Administration, the Public Health Service, and the Department of Defense) should ensure that their health care facilities adopt appropriate policies.

(23) The entry of an order not to resuscitate holds no necessary implications for any other therapeutic decisions, and the level or extent of health care that will be reimbursed under public or private insurance programs should never be linked to such orders.

(24) The education of health care professionals should ensure that they know how to help patients and family make ethically justified decisions for or against resuscitation; those responsible for professional licensure and certification may want to assess knowledge in these areas.

The Commission's Inquiry

When the Commission convened in January 1980, it decided to take up first its Congressional mandate to report on "the matter of defining death, including the advisability of developing a uniform definition of death."[5] In July 1981 the Commission reported its conclusions in *Defining Death*[6] and recommended the adoption of the Uniform Determination of Death Act (UDDA), which was developed in collaboration with the American Bar Association, the American Medical Association, and the National Conference of Commissioners on Uniform State Laws.[7]

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[5] 42 U.S.C. § 300v-1(a)(1)(B) (Supp. 1981).

[6] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, DEFINING DEATH, U.S. Government Printing Office, Washington (1981).

[7] The UDDA states:

> An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain

During hearings on this subject, the Commission learned that many people were troubled by the uncertainties about the correct care to provide for patients with serious deficits in "higher brain" functions—such as those required for thinking, communicating, and consciously responding to others or to the environment. Decisions about the care of such patients were seen to be at least as troubling as decisions about those who have permanently lost all brain functions. The most pointed example brought to the attention of the Commission is the group of patients who are so damaged as to be permanently devoid of any consciousness—the most severe brain damage compatible with life.[8] The Commission concluded that the situation of such patients—like Karen Quinlan—merited its attention. In *Defining Death*, the Commission stated an intention to report subsequently on the treatment of patients who are dying but not dead.[9]

The present study was undertaken not merely because of the study on the determination of death but also because of its broader relationship to work done by the Commission in several areas over the past three years. Under its mandate, the Commission is authorized to undertake investigation "of any other appropriate matter...consistent with the purposes of [its authorizing statute] on its own initiative."[10] Decisions about life-sustaining therapy involve the direct and concrete application of the principles of decisionmaking in medicine, which

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stem, is dead. A determination of death must be made in accordance with accepted medical standards.

Ten states and the District of Columbia have enacted the Uniform Determination of Death Act by statute. Cal. Uniform Determination of Death Act, amending Health and Safety Code §§ 7180-7183, 1982 New Laws 4451; Colo. Rev. Stat. § 12-36-136 (Supp. 1981); D.C. Code Ann. § 6-2401 (Supp. 1982); Idaho Code § 54-1819 (Supp. 1982); 1982 Md. Laws ch. 327; 1981 Miss. Laws ch. 410; Pa. Uniform Determination of Death Act, Pa. Acts 323 (1982); 1982 R.I. Pub. Laws ch. 411; 1982 Tenn. Pub. Acts ch. 763; Vt. Stat. Ann. tit. 18, § 5218 (Supp. 1981); Wisc. Stat. § 146.71 (Supp. 1982). The UDDA has been "adopted" through the case law by the highest court of two other states. *See* Swafford v. State, 421 N.E.2d 596, 602 (Ind. 1981) (for homicide law); *In re* Bowman, 94 Wash. 2d 407, 421, 617 P.2d 731, 738 (1982). This brings to 37 the number of jurisdictions that have recognized the determination of death through neurological criteria. For a listing of those states with other statutes, *see* DEFINING DEATH, *supra* note 6, at 65, 120-34.

[8] *See, e.g.*, testimony of Dr. Ronald Cranford, transcript of the 3rd meeting of the President's Commission (July 11, 1980) at 20, 23: "The persistent vegetative state..seems to me an even more complex and important issue....these cases of persistent vegetative state are going to become more frequent and they will continue to exist in that state for longer periods of time."

[9] DEFINING DEATH, *supra* note 6, at 4-5.

[10] 42 U.S.C. § 300v-1(a)(2) (Supp. 1981).

was the subject of the Commission's mandated study on informed consent.[11] Such decisions also illustrate the ways questions of equity in the allocation of often scarce and expensive resources are resolved, a subject addressed by the Commission in another mandated study.[12] The present Report thus represents an effort to apply the conclusions of two previous studies to a particular area of current concern, while also responding to some particularly difficult clinical and ethical problems noted in *Defining Death*.

The Commission received testimony and public comment on the subject of this Report at four public hearings in as many cities; witnesses from medicine, nursing, hospital administration, the social sciences, philosophy, theology, and law, as well as patients and family members, testified.[13] It also deliberated on partial drafts of the Report at eight Commission meetings. On December 15, 1982, a final draft was discussed and approved unanimously, subject to editorial corrections.

Overview of the Report

Part One of the Report examines the considerations common to all decisionmaking about life-sustaining therapy. Chapter One presents historical, cultural, and psychological information to illuminate the social context of the Report. Chapter Two first considers the importance of shared decisionmaking between provider and patient (in which the voluntary decisions of competent patients are ordinarily binding) and the considerations that arise when patients are inadequate decisionmakers, and then discusses constraints imposed by the community's need to ensure that life is protected and that wrongful death is deterred and punished. Traditional distinctions made between acceptable and unacceptable actions to forego treatment are critically scrutinized and their usefulness in sound decisionmaking is evaluated. Chapter Three analyzes additional constraints on patients' choices that arise from the actions of family and care-giving professionals, from society's pursuit of equitable allocation of resources, and from the policies and practices of health care institutions, which are often where these many forces come together.

In Part Two of the Report, several groups of patients whose situations currently raise special public policy concerns are considered. Chapter Four examines decisionmaking for incompetent patients generally, including "living wills" and other advance directives, intrainstitutional review (such as "ethics committees"), and court proceedings. Chapters Five

[11] MAKING HEALTH CARE DECISIONS, *supra* note 2.

[12] SECURING ACCESS TO HEALTH CARE, *supra* note 4.

[13] A detailed description of the Commission's inquiry appears in Appendix A, pp. 259-74 *infra*.

and Six look at the issues involved in treating two particular categories of incompetent patients—those who have permanently lost all consciousness and seriously ill newborns. Finally, Chapter Seven considers orders not to resuscitate hospitalized patients whose hearts stop beating and recommends institutional policies on such orders.

Extensive appendices follow the Report itself, beginning with a detailed account of the process followed by the Commission in its study. Appendix B reviews some of the medical aspects of caring for dying patients in a format intended to be helpful to clinicians, though it will also be of interest to people concerned with ethics and policy. The remainder of the Appendices consist of various documents that are cited in the text and that might otherwise be difficult for a reader to obtain, including the report of a national survey of hospital ethics committees undertaken for the Commission.

Making Treatment Decisions

I

The Setting of the Report

1

The Origins of Public Concern

Death comes to everyone. To a few, it comes suddenly and completely unexpectedly, but to most, it follows an opportunity for leave-taking and for directing to some extent the mode and timing of death.[1] Virtually all people who die in this country will have been under treatment by health care professionals who have, especially in the last four decades, developed powerful means to forestall death. This power is so dramatic that sometimes it seems that medicine aims first and foremost to conquer death. Physicians realize, of course, that the mission of vanquishing death is finally futile, but often they and their patients are quite determined to do all that is possible to postpone the event. Sometimes this objective so dominates care that patients undergo therapies whose effects do not actually advance their own goals and values. Specifically, the drive to sustain life can conflict with another fundamental (and arguably more venerable) objective of medicine—the relief of suffering.[2] Physicians and others who establish health care

[1] Approximately two million people die each year in the United States. The illnesses causing mortality most often are heart disease (34%), malignancies (22%), and cerebrovascular disease (7%). Traumatic death—including accidents, homicide and suicide—account for 13% of all deaths. Only the relatively few who die very suddenly from accident, heart attack, or stroke are likely to have been without medical attention. Dept. of Health, Education and Welfare, FACTS OF LIFE AND DEATH, U.S. Government Printing Office, Washington (1978) at 31-33.

[2] Physicians may not have recognized a duty to prolong life until fairly recently: "The treatise entitled *The Art* in the Hippocratic Corpus defines medicine as having three roles: doing away with the sufferings of the sick, lessening the violence of their diseases, and refusing to treat those who are overmastered by their diseases, realizing that in

policies and practices have come to recognize that the attempt to postpone death should at times yield to other, more important goals of patients.

Recent Changes in How and Where People Die. Until this century decisions about medical interventions to prolong life probably appeared more straightforward, for doctors had few effective therapies from which to choose.[3] For most patients, diagnosis of serious illness no longer connotes sure, fairly swift death, requiring of the physician "philosophy and sympathy, not science."[4] Between 1900 and the present, the causes of death have changed dramatically: communicable diseases have declined sharply while chronic, degenerative diseases have become much more prominent. At the turn of the century, influenza and pneumonia were the leading causes of death, followed by tuberculosis and "gastritis."[5] By 1976, these had been supplanted by heart disease, cancer, and cerebrovascular disease[6]—illnesses that occur later in life and that are ordinarily progressive for some years before death. Consequently, those facing death today are more likely to be aged and to be suffering from one or more ailments for which at least some potentially therapeutic interventions exist. "In this age of surgical derring-do and widespread use of drugs, almost no disease can be said any longer to have a 'natural history'."[7]

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such cases medicine is powerless." Darrell W. Admundsen, *The Physicians' Obligation to Prolong Life: A Medical Duty Without Classical Roots*, 8 HASTINGS CTR. REP. 23, 24 (Aug. 1978); Warren T. Reich, *The 'Duty' to Preserve Life*, 5 HASTINGS CTR. REP. 14 (April 1975).

One modern formulation of the physician's role toward the terminally ill is found in this statement from the American Medical Association. "The social commitment of the physician is to prolong life and relieve suffering. Where the observance of one conflicts with the other, the physician, patient, and/or family of the patient have the discretion to resolve the conflict." Judicial Council, CURRENT OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION, American Medical Association, Chicago (1982) at 9, *reprinted in* Appendix C, pp. 299-300 *infra*.

[3] Ivan L. Bennett, Jr., *Technology as a Shaping Force*, in John H. Knowles, ed., DOING BETTER AND FEELING WORSE: HEALTH IN THE UNITED STATES, W.W. Norton, New York (1977) at 128-29.

[4] Louis Lasagna, *The Prognosis of Death*, in Orville G. Brim, Jr. *et al.*, eds., THE DYING PATIENT, Russell Sage Foundation, New York (1970) at 67, 76.

[5] Monroe Lerner, *When, Why and Where People Die*, in Brim, *supra* note 4, at 5. *See also* Thomas M. Perry, *The New and Old Diseases: A Study of Mortality Trends in the United States, 1900-1969*, 63 AM. J. CLINICAL PATHOLOGY 453 (1975).

[6] FACTS OF LIFE AND DEATH, *supra* note 1.

[7] Lasagna, *supra* note 4, at 68.

Just as recent years have seen alterations in the underlying causes of death, the places where people die have also changed. For most of recorded history, deaths (of natural causes) usually occurred in the home.

> Everyone knew about death at first hand; there was nothing unfamiliar or even queer about the phenomenon. People seem to have known a lot more about the process itself than is the case today. The "deathbed" was a real place, and the dying person usually knew where he was and when it was time to assemble the family and call for the priest.[8]

Even when people did get admitted to a medical care institution, those whose conditions proved incurable were discharged to the care of their families. This was not only because the health care system could no longer be helpful, but also because alcohol and opiates (the only drugs available to ease pain and suffering) were available without a prescription.[9] Institutional care was reserved for the poor or those without family support; hospitals often aimed more at saving patients' souls than at providing medical care.[10]

As medicine has been able to do more for dying patients, their care has increasingly been delivered in institutional settings. By 1949, institutions were the sites of 50% of all deaths; by 1958, the figure was 61%; and by 1977, over 70%.[11] Perhaps 80% of the deaths in the United States now occur in

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[8] Lewis Thomas, *Dying as Failure*, 447 ANNALS AM. ACAD. POL. & SOC. SCI. 1, 3 (1980).

[9] The Harrison Act of 1914 restricted access to narcotics, making them available only through a physician's prescription. Harrison Act, 38 Stat. 785 (1914), as amended 26 U.S.C.; Alfred R. Lindesmith, THE ADDICT AND THE LAW, Random House, New York (1965) at 3-8. At the turn of the century many of the widely available elixers and patent medicines contained substantial quantities of narcotics. Nicholas N. Kittrie, THE RIGHT TO BE DIFFERENT, Johns Hopkins Univ. Press, Baltimore, Md. (1971) at 216-17; James Harvey Young, THE TOADSTOOL MILLIONAIRES, Princeton Univ. Press, Princeton, N.J. (1961). *See also* David E. Kyvig, REPEALING NATIONAL PROHIBITION, Univ. of Chicago Press, Chicago (1979) at 33 (describing physicians' reactions to restrictions on medicinal use of alcohol during prohibition).

[10] "The first hospitals for the sick...remained, of course, the least preferred setting for medical treatment, and people with sufficient funds received care at home. But by the end of the colonial period, the almshouse had become a hospital for the poor." David J. Rothman, THE DISCOVERY OF THE ASYLUM: SOCIAL ORDER AND DISORDER IN THE NEW REPUBLIC, Little, Brown, Boston (1971) at 43-45. John H. Knowles, *The Hospital*, in LIFE AND DEATH AND MEDICINE, W.H. Freeman & Co., San Francisco (1973) at 91.

[11] Lerner, *supra* note 5, at 22; Jack M. Zimmerman, *Experience with a Hospice-Care Program for the Terminally Ill*, 189 ANNALS SURGERY 683 (1979).

hospitals and long-term care institutions, such as nursing homes.[12] The change in where very ill patients are treated permits health care professionals to marshall the instruments of scientific medicine more effectively. But people who are dying may well find such a setting alienating and unsupportive.

> Patients who are known to be dying are segregated as much as possible from all the others, and...doctors spend as little time in attendance as they can manage... When [doctors] avert their eyes it is not that they have lost interest, or find their attendance burdensome because wasteful of their talents; it is surely not because of occupational callousness. Although they are familiar with the business, seeing more of it at first hand than anyone else in our kind of society, they never become used to it. Death is shocking, dismaying, even terrifying. A dying patient is a kind of freak. It is the most unacceptable of all abnormalities, an offense against nature itself.[13]

Meeting Patients' Needs. With the process of dying prolonged and increasingly institutionalized, new concerns have arisen from and on behalf of dying patients. As in all areas of medicine, care of these patients is shaped by the varying degrees of uncertainty regarding diagnosis and prognosis. On the one hand, for most patients death is not unanticipated. One study, for example, found that half the population dies of an illness diagnosed at least 29 months earlier[14]; chronic conditions were the cause of 87% of all deaths in 1978.[15] On the other hand, dying follows no regular path.[16] The varied and somewhat unpredictable nature of the physical course of a

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[12] In a review of 35,381 cancer deaths in Cuyahoga County, Ohio, homes during the period 1957-1974, 65% of the people died in hospitals, 15% in nursing homes, and 20% at home. Arthur Flynn, *Where Do Cancer Patients Die*?, 5 J. Community Health 126 (Winter 1979). *See also* John M. Hinton, *Comparison of Places and Policies for Terminal Care*, 1 Lancet 29 (1979); Roger Pritchard, *Dying: Some Issues and Problems*, 164 Annals N.Y. Acad. Sci. 707 (1969).

[13] Thomas, *supra* note 8, at 2.

[14] Raymond S. Duff and August B. Hollingshead, Sickness and Society, Harper & Row, New York (1968) at 307.

[15] Anne R. Somers, *Long-Term Care for the Elderly and Disabled*, 307 New Eng. J. Med. 221 (1982) (quoting Dorothy P. Rice of the National Center for Health Statistics).

[16] Strauss and Glaser have developed a theory involving each patient's "dying trajectory" to describe this process. Barney G. Glaser and Anselm L. Strauss, Time for Dying, Aldine Pub. Co., Hawthorne, N.Y. (1968). "It plunges straight down, it moves slowly but steadily downward; it vacillates slowly, moving slightly up and down before diving downward radically; it moves slowly down at first, then hits a long plateau, then plunges abruptly to death." Anselm L. Strauss and Barney G. Glaser, *Patterns of Dying*, in Brim, *supra* note 4, at 129, 131.

dying patient is often a major source of anxiety to the patient, family, and care givers.

Patients frequently are afraid of symptoms and conditions, especially pain,[17] that may accompany the dying process. With appropriate medical management, many of these fears can be allayed. Patients who fear pain do so most often when it is out of control, overwhelming, or chronic, when it comes from an unknown source, or when it warns of devastating injury or death.[18] Each of these sources of fear can be treated. People at the forefront of the hospice movement, for example, have demonstrated that presently available drugs and other techniques can reduce even overwhelming pain to acceptable levels.[19] Some physicians may previously have withheld drugs to control pain out of a fear of addiction,[20] a concern that is unwarranted for dying patients.[21] Moreover, other uncomfortable or dangerous side effects of adequate pain medication can

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[17] Peter G. Wilson, *Anxiety and Depression in Elderly and Dying Patients*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1011 (Sept. 1982). *See generally*, Patrick B. Friel, *Death and Dying*, 97 ANNALS INT. MED. 767 (1982).

[18] Eric J. Cassell, *The Nature of Suffering and the Goals of Medicine*, 306 NEW ENG. J. MED. 639 (1982); Laurence B. McCullough, *Pain, Suffering and Life Extending Technologies*, in Robert M. Veatch, ed., LIFE SPAN, Harper & Row, New York (1979) at 118.

[19] Some of the techniques to control pain and other symptoms are given in Appendix B, pp. 275-97 *infra*. St. Christopher's Hospice reports complete control of pain in more than 99% of its dying patients. Cicely M. Saunders, *Current Views on Pain Relief and Terminal Care*, in Martin A. Swerdlow, ed., THE THERAPY OF PAIN, J.B. Lippincott Co., Philadelphia (1981) at 215.

Just as people have different understandings of death, so do they view pain differently:

> According to Christian teaching, however, suffering, especially during the last moments of life, has a special place in God's saving plan; it is in fact a sharing in Christ's Passion and a union with the redeeming sacrifice which he offered in obedience to the Father's will. Therefore one must not be surprised if some Christians prefer to moderate their use of painkillers, in order to accept voluntarily at least a part of their suffering and thus associate themselves in a conscious way with the sufferings of Christ crucified.

Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Vatican City (1980) at 8; *reprinted in* Appendix C, pp. 300-07 *infra*.

[20] Gerald Klerman has termed this hesitance on the part of physicians, "pharmacological Calvinism." Gerald L. Klerman, *Psychotropic Drugs as Therapeutic Agents*, 2 HASTINGS CTR. STUDIES 80, 91-2 (Jan. 1974).

[21] Marcia Angell, *The Quality of Mercy* (Editorial), 306 NEW ENG. J. MED. 98 (1982); Richard M. Marks and Edward J. Sachar, *Undertreatment of Medical Inpatients with Narcotic Analgesics*, 78 ANNALS INT.

often be mitigated by careful attention to drug schedule, the strength of the medication, or a combination of these.[22] Symptoms such as nausea, anxiety, constipation, insomnia, and shortness of breath can also usually be ameliorated.[23] Simple attention to details such as skin care, oral hygiene, and proper positioning can greatly improve the lives of patients who are dying.

In the past several decades, the emotional and psychic course of dying patients has also received increasing attention.[24] The concern of the public as well as health care professionals has been evidenced by conferences, courses and training seminars, and publications such as *On Death and Dying*, a landmark book by Dr. Elisabeth Kübler-Ross published in 1969.[25] Critics of her work point out that dying patients do not all pass in lock-step fashion through the five psychological stages (denial and isolation, anger, bargaining, depression, and acceptance) that Dr. Kübler-Ross observed during counseling sessions, and that her theory has yet to be confirmed by systematic research. Although Dr. Kübler-Ross emphasized that patients in all stages continue to evidence hope, the very notion of "stages" is potentially misleading since they are not independent, in the sense of a patient being "in" one stage or another. Perhaps most important, experience shows that acceptance is not always possible or appropriate for a patient.[26] Eschewing the theory of stages of death, one thanatologist sees instead "a complicated clustering of intellectual and affective states, some fleeting, lasting for a moment or

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MED. 173 (1973); Jane Porter and Hershel Jick, *Addiction Rate in Patients Treated with Narcotics*, 302 NEW ENG. J. MED. 123 (1980).

[22] Robert G. Twycross, *Relief of Pain*, in Cicely M. Saunders, ed., THE MANAGEMENT OF TERMINAL DISEASE, Edward Arnold Publishers, Ltd., London (1978) at 65.

[23] Ned H. Cassem and Rege S. Stewart, *Management and Care of the Dying Patient*, 6 INT'L. J. PSYCHIATRY IN MEDICINE 293, 299 (1975); A.G.O. Crowther, *Management of Other Common Symptoms in the Terminally Ill*, in Eric Wilkes, ed., THE DYING PATIENT, George A. Bogden & Son, Inc., Ridgewood, N.J. (1982) at 209; Mary J. Baines, *Control of Other Symptoms*, in Saunders, *supra* note 22, at 99.

[24] Michele Vovelle, *Rediscovery of Death Since 1960*, 447 ANNALS AM. ACAD. POL. & SOC. SCI. 89 (1980).

[25] Elisabeth Kübler-Ross, ON DEATH AND DYING, Macmillan Pub. Co., New York (1969).

[26] Michael A. Simpson, *Therapeutic Uses of Truth*, in Wilkes, *supra* note 23, at 255, 258; Ned H. Cassem, *The Dying Patient*, in Thomas P. Hackett and Ned H. Cassem, eds., MASSACHUSETTS GENERAL HOSPITAL HANDBOOK OF GENERAL HOSPITAL PSYCHIATRY, C.V. Mosby Co., St. Louis, Mo. (1978) at 300.

a day or a week, set not unexpectedly against a backdrop of that person's total personality, 'his philosophy of life'."[27]

Views of Death. Dying patients often are not entirely averse to the prospect of death,[28] which may be seen as preferable to prolonging an inexorable process of suffering or as less important than other concerns (personal salvation, the welfare of loved ones, and so forth). People's perceptions of the nature and meaning of death, especially in this pluralistic society, are quite diverse. For some, life is infinitely important and death is always to be opposed:

> The value of human life is infinite and beyond measure, so that a hundred years and a single second are equally precious.[29]

For some, life is the norm and death an oddity or annoyance:

> To make matters worse, the process of dying cannot even be treated as a tragedy since our Doing and mastery-over-Nature values make it seem more like technical failure. Tragedy, in our society, is something that should have been avoided rather than something to be appreciated. The implication is that someone slipped up or that research simply has not yet got around to solving this kind of thing. Thus dying is covered over with optimistic or reassuring statements and the dying person is scarcely given the opportunity to make the most of his position.[30]
>
> All men must die: but for every man his death is an accident and, even if he knows it and consents to it, an unjustifiable violation.[31]

Some have noted that the inevitability of death is what gives life meaning or purpose:

> Protect me
> From a body without death. Such indignity
> Would be outcast, like a rock in the sea.

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[27] Edwin S. Shneidman, *Death Work and Stages of Dying*, in Edwin S. Shneidman, ed., DEATH: CURRENT PERSPECTIVES, Mayfield Pub. Co., Palo Alto, Calif. (1976) at 446.

[28] *See, e.g.*, C.M. Farquhar, *Attitudes and Beliefs Concerning Life and Death of Elderly Persons*, 92 NEW ZEALAND MED. J. 107 (1980); David L. Jackson and Stuart Youngner, *Patient Autonomy and "Death with Dignity"*, 301 NEW ENG. J. MED. 404 (1979); L. Witzel, *Behavior of the Dying Patient*, 2 BRIT. MED. J. 81 (1975).

[29] Immanuel Jakobovitz, JEWISH MEDICAL ETHICS, Bloch Pub. Co., New York (1959) at 46.

[30] John Spiegel, *Cultural Variations in Attitudes Toward Death and Disease*, in George H. Grosser *et al.*, eds., THE THREAT OF IMPENDING DISASTER, M.I.T. Press, Cambridge, Mass. (1964) at 297.

[31] Simone de Beauvoir, A VERY EASY DEATH, G.P. Putman's Sons, New York (1966), *reprinted in* Shneidman, *supra* note 27, at 523, 526.

> But with death, it can hold
> More than time gives it, or the earth shows it.[32]

> Death forces us to shore up, personally and aggregatively, the conviction of life; that we persist and survive, as at least minimally rational creatures, confirms the pragmatic adequacy of our beliefs.[33]

For some, death is the release of the soul from its body:

> The soul which is pure at departing...departs to the invisible world—to the devine and immortal and rational: Hither arriving, she is secure of bliss and is released from the error and folly of men, their fears and wild passions and all other human ills, and forever dwells, as they say of the initiated, in company with the gods.[34]

The perspectives on death are as numerous as the philosophies and religions that give them birth. And for each perspective there is a complementary set of values and priorities in the medical care of dying patients. Someone who holds that every second of life under any circumstances is worth living, for example, will make very different decisions than a person who is accepting of death.[35]

The view that there is no one way to die that is right for all persons has ancient roots:

> Just as I choose a ship to sail in or a house to live in, so I choose a death for my passage from life....Nowhere should we indulge the soul more than in dying....A man's life should satisfy other people as well, his death only himself, and whatever sort he likes best.[36]

Under modern conditions, to achieve some harmony between an individual's death and personal values throughout life will probably entail not only awareness of personal values but also

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[32] Christopher Fry, THE DARK IS LIGHT ENOUGH, Oxford Univ. Press, London (1954) at 89.

[33] Joseph Margolis, *Death*, in NEGATIVITIES: THE LIMITS OF LIFE, Charles E. Merrill Pub. Co., Columbus, Oh, (1975), *reprinted in* Tom L. Beauchamp and Seymour Perlin, eds., ETHICAL ISSUES IN DEATH AND DYING, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1978) at 357, 363.

[34] Plato, *Phaedo*, in Irwin Edman, ed., THE WORKS OF PLATO, Modern Library, New York (1928) at 141.

[35] "An appropriate death, in brief, is a death that someone might choose for himself—had he a choice." Avery D. Weisman, *Appropriate and Appropriated Death*, in ON DYING AND DENYING: A PSYCHIATRIC STUDY OF TERMINALITY, Behavioral Publications, Inc., New York (1972) at 41; Lauren E. Trombley, *A Psychiatrist's Response to a Life-Threatening Illness*, in Shneidman, *supra* note 27, at 506; H. Tristram Engelhardt, Jr., *Tractatus Artis Bene Moriendi Vivendique: Choosing Styles of Dying and Living*, in Virginia Abernathy, ed., FRONTIERS IN MEDICAL ETHICS, Ballinger Pub. Co., Cambridge, Mass. (1980) at 9.

[36] Seneca, *Suicide*, in THE STOIC PHILOSOPHY OF SENECA, W.W. Norton, New York (Moses Hadas trans. 1958) at 506.

the sensitivity and compassion of others and the tolerance of a society willing to allow a fair range of choice—both for people to find and create meaning in living while dying, and for survivors to incorporate and interpret their loss.

Achieving this harmony is made more complex because of an apparently unavoidable tension that accompanies the medical care of dying patients. It is a tension that persists even when both the general society and health care professionals agree that avoiding death should not always be the preeminent goal of therapy and that assisting each patient to achieve a personally appropriate death is among the professionals' obligations. Once someone realizes that the time and manner of death are substantially under the control of medical science, he or she wants to be protected against decisions that make death too easy and quick as well as from those that make it too agonizing and prolonged. Yet such a "golden mean" defies ready definition, both in theory and often in practical application in individual cases.[37] Each case is different, both objectively and in the subjective experience of the patient, so definitions of "too quick" and "too long" vary widely. This does not, however, preclude setting forth some general guidelines and policy tools.

Considerations in Framing Social Policy

The Commission uses the term public policy in its broadest sense, which includes all the various rules, norms, laws, and practices that a society employs in a given area. Regulations may be formal, such as statutes enforced according to specified procedures, or informal, as in the expectations regarding acceptable professional behavior that health care professionals absorb while learning other things.[38] A public policy also exists when society chooses not to intervene in private actions. Indeed, a major issue in establishing wise public policies on life-sustaining treatment is the degree to which the community and its agents should be involved in medical decisionmaking.

Public policy is mediated through a variety of societal practices and institutions: governmental bodies (both legislative and regulatory), health care professionals and institutions (individually and collectively), organized religions, and other social groups. Yet the people who must implement such

[37] When 205 physicians in one study were presented with a hypothetical case, the range of assessments was striking, with those who favored and those against aggressive treatment offering the same reasons but projecting very different views of the patient's future. Robert A. Pearlman, Thomas S. Inui, and William Carter, *Variability in Physician Bioethical Decisionmaking: A Case Study of Euthanasia*, 97 Annals Int. Med. 420 (1982).

[38] *See, e.g.*, Charles L. Bosk, Forgive and Remember: Managing Medical Failure, Univ. of Chicago Press, Chicago (1979).

policies are often the directly affected patients and their families.

The Disservice Done by Empty Rhetoric. Discussions of life-sustaining treatment have often been confused by the use of slogans and code words. As a general matter, the issues can be understood much better if the exact meaning of these rhetorical devices is spelled out. Phrases like "right to die," "right to life," "death with dignity," "quality of life," and "euthanasia" have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred.

In recent years, for example, many have commented on the claim that patients have a "right to die with dignity."[39] Much can and should be done to ensure that patients are treated with respect and concern throughout life. Insofar as "death with dignity" means that the wishes of dying patients are solicited and respected, it is a concept the Commission endorses.[40] Many who use the phrase seem to go well beyond this, however, to a vision in which everyone is guaranteed a peaceful and aesthetically appealing death. This is clearly beyond reach; a fair proportion of dying patients are confused, nauseated, vomiting, delirious, bleeding, or breathless. Avoiding these distressing symptoms is not always possible; likewise, naturalness may have to be sacrificed since mechanical assistance is sometimes required to ensure comfort at the end of life.[41] Thus, the apparent appeal of the slogan "dignified death" often disappears before the reality of patients' needs and desires. Comparable problems arise with other slogans that are frequently heard in discussions on life-sustaining treatment.[42]

Other phrases—though useful as general descriptions—are similarly unacceptable when an unambiguous definition is

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[39] *See, e.g.*, Stephen L. Kuepper, THE EUTHANASIA MOVEMENT: A BRIEF HISTORY OF THE ORGANIZED EUTHANASIA MOVEMENT IN THE UNITED STATES (1979) (unpublished manuscript, on file with the Society for the Right to Die, New York); Ivan Illich, *The Political Use of a Natural Death*, 2 HASTINGS CTR. STUDIES 3 (Jan. 1974); Marya Mannes, LAST RIGHTS: A PLEA FOR THE GOOD DEATH, William Morrow, New York (1974); Patrick Francis Sheehy, ON DYING WITH DIGNITY, Pinnacle Books, New York (1981). *But see* Jackson and Youngner, *supra* note 28.

[40] *See* pp. 46-51 *infra*.

[41] Robert M. Veatch, DEATH, DYING AND THE BIOLOGICAL REVOLUTION, Yale Univ. Press, New Haven, Conn. (1976) at 277-305; Paul Ramsey, *The Indignity of Death with Dignity*, 2 HASTINGS CTR. REP. 47 (May 1974). *See also* Appendix B, pp. 275-97 *infra*.

[42] *See, e.g.*, Daniel Callahan, *Natural Death and Public Policy*, and James Childress, *Further Reflections on Natural Death and Public Policy*, in Robert M. Veatch, ed., LIFE SPAN: VALUES AND LIFE-EXTENDING TECHNOLOGIES, Harper & Row, San Francisco (1979) at 162, 176.

required. For example, attempts—such as those in several statutes[43]—to make the obligations of patients and providers different when a patient is "terminally ill" are dubious for several reasons. First, although a decision to undertake a life-sustaining treatment will frequently depend on whether the patient believes the treatment is likely to extend life substantially enough to be worth its burdens, patients with similar prognoses evaluate relevant facts very differently. The closeness of death may be strongly felt by someone who has only a remote chance of dying soon, while for another person it may not seem imminent until his or her organs have nearly ceased to function. Moreover, prognostication near the end of life is notoriously uncertain.[44] At best, confidence in predicting death is possible only in the final few hours. Patients with the same

[43] Natural Death Acts have usually tried to define a class of patients who have "incurable injury, diseases, or illness...where the application of life-sustaining procedures would serve only to prolong the dying process." Medical Treatment Decision Act, *reprinted in* Appendix D, pp. 313-17 *infra*. The 1982 amendments to the Medicare program provide much more substantial reimbursement for "palliation and management" of "terminally ill" patients (defined as those for whom death is expected within six months) than for treatment of disease for these patients or for any treatment of other patients. § 122, Part II, Tax Equity and Fiscal Responsibility Act, Pub. L. No. 97-248 (1982). These points are discussed more fully in Chapters Three and Four *infra*. *See also* Paul Ramsey, THE PATIENT AS PERSON, Yale Univ. Press, New Haven, Conn. (1970) at 113.

[44] "Physicians' predictions of prognosis were relatively inaccurate, with actual survival plus or minus one month coinciding with that predicted in only 16% of patients. Except in patients who were very ill and had short prognosis of three to four months, survival was consistently underestimated." Linda J. Aiken and Martita M. Marx, *Hospices: Perspectives on the Public Policy Debate*, 37 AM. PSYCHOLOGIST 1271, 1275 (1982) (reporting data from J.W. Yates, F.P. McKegney, and L.E. Kun, *A Comparative Study of Home Nursing Care of Patients with Advanced Cancer*, Proceedings of the Third National Conference on Human Values of Cancer, American Cancer Society, New York, 1982).

The subjective nature of prognoses affects the types of treatment that are encouraged, which in turn affects patients' outcome. In one study, physicians who preferred to intubate and artificially ventilate a patient with severe chronic lung disease projected that the patient would survive about 15 months; other physicians who decided against artificial ventilation when presented with the same case predicted that, even with artificial life support, the patient had only 6 months to live. Pearlman, Inui, and Carter, *supra* note 37. *See also* J. Englebert Dunphy, *Annual Discourse—On Caring for the Patient with Cancer*, 295 NEW ENG. J. MED. 313, 314 (1976); Mark Siegler, *Pascal's Wager and the Hanging of Crepe*, 293 NEW ENG. J. MED. 853 (1975); *cf.* Arno G. Motulsky, *Biased Ascertainment and the Natural History of Disease*, 298 NEW ENG. J. MED. 1196 (1978).

stage of a disease but with different family settings, personalities, and "things to live for" actually do live for strikingly varied periods of time.[45] It seems difficult to devise or to justify policies that restrict people's discretion to make appropriate decisions by allowing some choices only to "terminally ill" patients or by denying them other choices.

Although the Commission has attempted to avoid rhetorical slogans so as to escape the ambiguities and misunderstandings that often accompany them, it uses "dying" and "terminally ill" as descriptive terms for certain patients, not as ironclad categories. There seem to be no other terms to use for a patient whose illness is likely to cause death within what is to that person a very short time. Of course, the word "dying" is in some ways an unilluminating modifier for "patient"—since life is always a "terminal" condition—and further refinements, such as "imminently," do little to clarify the situation. Therefore, words like "dying" are used in this Report in their colloquial sense and with a caution against regarding them as a source of precision that is not theirs to bestow.

Underlying Values. In its work on the ethical issues in health care the Commission discussed the importance of three basic values: self-determination, well-being, and equity. The concepts are not all-encompassing; nor was any attempt made to relate them in a hierarchical fashion. In *Making Health Care Decisions*, the Commission focused almost entirely upon the values of self-determination and well-being[46]; in *Securing Access to Health Care*, principally upon considerations of equity.[47] In this Report, the Commission examines treatment situations in which all three values are intimately involved.

The primary goal of health care in general is to maximize each patient's well-being. However, merely acting in a patient's best interests without recognizing the individual as the pivotal decisionmaker would fail to respect each person's interest in self-determination—the capacity to form, revise, and pursue his or her own plans for life. Self-determination has both an instrumental value in achieving subjectively defined well-being and an intrinsic value as an element of personal worth and integrity.

Given the special importance of health care in promoting individuals' well-being and opportunities, the Commission also

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[45] E. Mansell Pattison, *The Will to Live and the Expectation of Death*, in E. Mansell Pattison, ed., THE EXPERIENCE OF DYING, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1977) at 61.

[46] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, MAKING HEALTH CARE DECISIONS, U.S. Government Printing Office, Washington (1982).

[47] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, SECURING ACCESS TO HEALTH CARE, U.S. Government Printing Office, Washington (1983).

concluded that society has a moral obligation to ensure that everyone has access to an adequate level of care and is able to obtain such care without excessive burdens (in terms of financial or time expenditures). Since differences in health status are largely determined by natural and social contingencies beyond an individual's control and are so unevenly distributed that some people are unable through their own efforts to obtain adequate care, the moral obligation to ensure equitable access rests with society as a whole. This obligation is particularly acute when health care is needed to sustain life itself.

Though a given decision will often serve all relevant values, sometimes conflict occurs. When the conflicts that arise between a competent patient's self-determination and his or her apparent well-being remain unresolved after adequate deliberation, a competent patient's self-determination is and usually should be given greater weight than other people's views on that individual's well-being. Similarly, while a competent patient's choice about treatment is usually more compelling than claims based on resource allocations, considerations of equitable access to health care in society will in fact partially determine the availability of options for a particular patient. Fair treatment of individuals necessitates basing decisions about availability and funding on defensible principles, and then implementing decisions through general rules and institutional policies that are insulated from the subjectivity of ad hoc decisions.

General Rules and Specific Cases. Although good public policy should reflect morally sound treatment of the individual cases that the policy concerns, the many distinctions among different cases that might be made in a careful, complete moral analysis cannot usually be included in a manageable public policy. Yet general rules are adopted to govern the behavior of many people with diverse values and goals in a manner that is morally acceptable in the vast majority of cases and that tends to permit only the most acceptable errors. But the weight of certain ethical considerations is changed when they are applied to matters of general public policy instead of merely to the private concerns of individuals. Consequently, policies that are predominantly procedural rather than substantive are often favored as a means of attempting to allocate responsibility in a way that allows decisionmakers to take account of the full range and subtlety of each case's morally relevant features.

As in so many other areas, there is tension between substance and procedures in making policies about foregoing life-sustaining treatment. Decisions are commonly made under adverse conditions; the individuals who make them have varying capacities for judgment and their disinterest and goodwill are sometimes imperfect. Caution is warranted, then,

in considering procedural policies that fail to place some substantive constraints on the decisionmakers. For the same reasons, however, policies that *do* contain substantive criteria for decisions may be subject to misuse and abuse. To limit the potential for both well-intentioned misapplication and ill-intentioned abuse, justifiable social and legal policies in this area (as elsewhere) may forbid certain classes of actions that include cases in which the forbidden act would actually be morally justified, while at the same time allowing other classes that include cases in which the permitted act would be morally wrong. The problem, then, is determining which guidelines and procedures are most likely to produce optimal decisions—in this case, the best balance between overuse and underuse of life-sustaining treatment.

Consistent with this goal, the conflict between the careful assessments of the concerned parties in a particular case and the demands of public policy should be minimized. Otherwise patients, providers, and families will continually be acting contrary either to generally accepted, and often legally enforced, public policy or to their own responsible assessment of a situation.

"Slippery Slope" Arguments. An important concern regarding the potential of any policy to cause unintended harm is captured in the phrase "slippery slope." This argument cautions against taking a first step that is itself ethically justified when doing so is expected to lead to the acceptance of other actions that are not likewise justified.[48] If the slope is indeed slippery and no likely stopping points exist to provide a toehold, then the wisest course may be to avoid taking the first step.

Slippery slope arguments are prominent whenever the protection of human life is at stake. Some people urge, for example, that intentional killing should be allowed if a person who will die very soon of an untreatable illness that is causing great and unrelievable suffering wants to die but is physically incapable of ending his or her own life.[49] This position would

[48] An interesting view of the "slippery slope" argument in the context of *in vitro* fertilization can be found in Samuel Gorovitz, *In Vitro Fertilization: Sense and Nonsense and a Reply to Leon Kass*, in Ethics Advisory Board, Dept. of Health, Education and Welfare, HEW Support of Research Involving Human In Vitro Fertilization and Embryo Transfer, U.S. Government Printing Office, Washington (1979). *See also*, Peter Steinfels and Carol Levine, eds., *Biomedical Ethics and the Shadow of Nazism*, 6 Hastings Ctr. Rep. (Special Supp. Aug. 1976).

[49] *See, e.g.*, Marvin Kohl, ed., Beneficent Euthanasia, Prometheus Books, Buffalo, N.Y. (1975); James Rachels, *Active and Passive Euthanasia*, 292 New Eng. J. Med. 78 (1975); Bonnie Steinbock, *The*

clearly be opposed by people who hold that deliberate killing of an innocent person is always wrong.[50] But it would also be opposed by those who might be willing to allow killing in such a situation but who fear that doing so would put society on a slippery slope because it would lead to killing in other, unjustifiable circumstances.[51]

For such an argument to be persuasive, however, much more is needed than merely pointing out that allowing one kind of action (itself justified) could conceivably increase the tendency to allow another action (unjustified). Rather, it must be shown that pressures to allow the unjustified action will become so strong once the initial step is taken that the further steps are likely to occur. Since such evidence is commonly quite limited, slippery slope arguments are themselves subject to abuse in social and legal policy debate.

Obviously, slippery slope arguments must be very carefully employed lest they serve merely as an unthinking defense of the status quo.[52] The cost of accepting such an argument is the

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Intentional Termination of Life, 6 ETHICS, SCI., & MED. 59 (1979); Derek Humphry, LET ME DIE BEFORE I WAKE, Hemlock, Santa Monica, Calif. (1981).

[50] *See, e.g.*, Paul Ramsey, ETHICS AT THE EDGES OF LIFE, Yale Univ. Press, New Haven, Conn. (1978); Arthur Dyck, *An Alternative to the Ethic of Euthanasia*, in Robert H. Williams, ed., TO LIVE AND TO DIE, Springer-Verlag, New York (1973) at 98; *Declaration on Euthanasia* (1980), *reprinted in* Appendix C, pp. 300-07 *infra*.

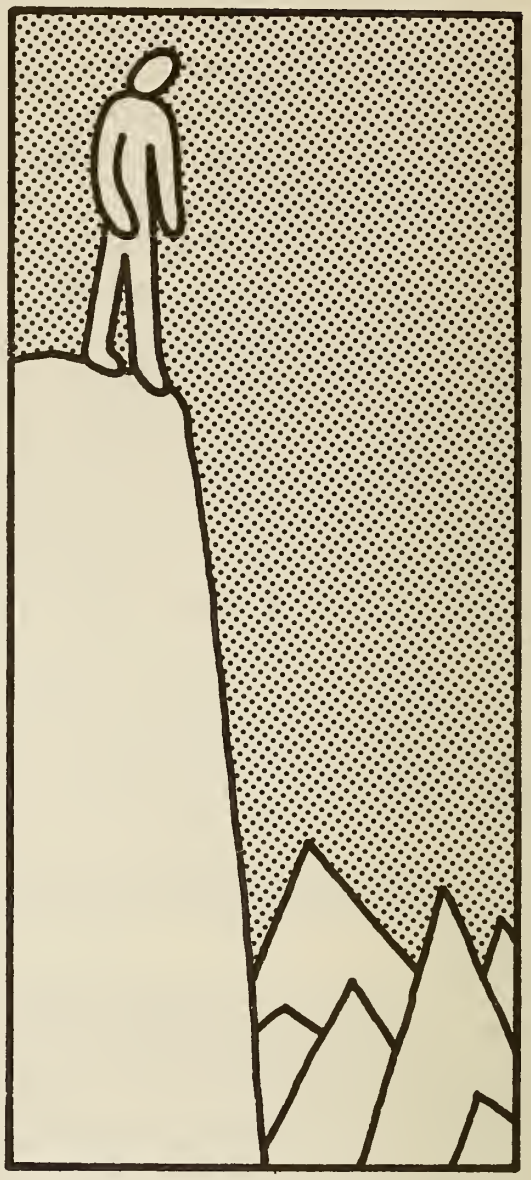
[51] *See, e.g.*, Yale Kamisar, *Euthanasia Legislation: Some Non-Religious Objections*, 42 MINN. L. REV. 969 (1958).

[52] I guess the slippery slope must have been the Swiss philosopher's answer to the Arabic philosopher's camel's nose [under the tent]....It seems to me that it is a bogeyman that is brought out in every discussion—again it's part of the hard-case problem....

It then occurred to me that there was not a single problem that I was concerned about that didn't exist on a spectrum, and that any time you draw a line on any spectrum some damn fool can get up and point to the two things proximal to that line and say, "You mean, Dr. So-and-so, you think there's a difference between X and Y." And, of course, there isn't a difference between X and Y, because when you're on a spectrum, wherever you draw the line, you're going to find two proximal points that are almost identical.... You...[run the risk of going] all through your life never drawing a line.

Testimony of Dr. Willard Gaylin, transcript of 21st meeting of the President's Commission (June 10, 1982) at 144-45.

We do not always possess clear natural lines. Such a realization is sometimes thought to imply that all distinctions are useless, so long as they are not mirrored in nature. But it is crucial to see that, even though a line is not drawn in nature, it may well be needed in practice....All social policy requires the



continued prohibition of some conduct that is actually acceptable. Nevertheless, the Commission has found that in the area of concern of this Report, in which human life is at issue, valid concerns warrant being especially cautious before adopting any policy that weakens the protections against taking human life.

The Role of Law. Law is one of the basic means through which a society translates its values into policies and applies them to human conduct. Using the general rules embodied in statutes, regulations, and court decisions, society attempts judiciously to balance the degree to which various values may be pursued and to arbitrate situations in which serving one fully justified goal entails failing to serve another. With respect to foregoing life-sustaining treatment, law simultaneously allows such decisions (as an expression of the value of self-determination and well-being), circumscribes the practice (to safeguard well-being), and shapes social institutions and government programs (to advance equity and well-being and to protect self-determination).

The legal system frames these issues in several ways. The outer limits of acceptable behavior are set by the criminal law, which encompasses not merely the rules set forth in the statute books (concerning intentional or negligent homicide, for example) but also the discretion of prosecutors and the decisions of judges and jurors in individual cases. In civil law, comparable rules can be invoked by individuals either after the fact (in

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> drawing of lines....Prohibitions have to be established and distinctions made even where human affairs are uncertain and hard to classify.

Sissela Bok, *Death and Dying: Euthanasia and Sustaining Life: Ethical Views*, in 1 ENCYCLOPEDIA OF BIOETHICS, The Free Press, New York (1978) at 268, 277.

damage actions) or before a decision is made about treatment (through the appointment of a guardian or through an injunction). Public law, statutory and regulatory, enters in the form of rules on the administration, funding, and regulation of governmental and private programs. Underlying all these areas are claims asserted as constitutional rights, perhaps most importantly the right of privacy, described as the "interest in independence in making certain kinds of important decisions."[53] The constitutional right of privacy encompasses a far broader range of interests than those implicated in health care decisionmaking—so broad that it is probably better to think of it as a variety of privacy interests rather than as one indivisible right.[54]

In its seminal *Quinlan* opinion, the New Jersey Supreme Court used this right as the cornerstone of its reasoning:

> It is the issue of the constitutional right of privacy that has given us most concern, in the exceptional circumstances of this case....Supreme Court decisions have recognized that a right of personal privacy exists....Presumably this right is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances.[55]

The *Quinlan* court recognized that although it is substantial, the right of privacy in this context is not absolute and may give way to "interests of the State in...the preservation and sanctity

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[53] Whalen v. Roe, 429 U.S. 589, 598 (1977) (footnote omitted). The decisions that have received greatest attention concern marriage and parenting. *See, e.g.*, Eisenstadt v. Baird, 405 U.S. 438 (1972) (striking regulation limiting sale of contraceptives to married couples); Griswold v. Connecticut, 381 U.S. 479 (1965) (striking state regulation of sale and use of contraceptives by married couples); Skinner v. Oklahoma, 405 U.S. 438 (1942) (limited state's use of sterilization); Pierce v. Society of Sisters, 268 U.S. 510 (1925) (parental right to direct education and upbringing of children upheld).

[54] Laurence Tribe, AMERICAN CONSTITUTIONAL LAW, Foundation Press, Mineola, N.Y. (1978) at 886-990.

[55] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 662-63, *cert. denied*, 429 U.S. 922 (1976).

Some commentators have, however, expressed doubts about framing these issues in terms of Constitutional rights.

> The Quinlan decision seems to have been a premature if reasonably thoughtful constitutionalization of a difficult and still fluid area....Viewed as a prod to intensive legislative consideration, the decision's guidelines seem defensible. But by casting its holding in federal constitutional terms, the New Jersey court may have needlessly foreclosed more intelligent legislative solutions in that state....This case did not involve a law or policy selectively burdening less powerful groups in the society.

Tribe, *supra* note 54, at 937 (citations omitted).

of human life and defense of the right of the physician to administer medical treatment according to his best judgment."[56] In other cases, courts have recognized two more counterweights—the protection of the interests of innocent third parties (especially the financial and emotional interests of minor children) and the societal interest in preventing suicide.[57]

In most decisions to forego life-sustaining treatment, these four state interests are quite attenuated. The preeminent one—that of preserving life—must be considered in concert with concerns about the suffering inflicted upon a dying individual and society's general "regard for human dignity and self-determination."[58] Likewise, the emotional and financial interests of dependents and family members are unlikely to be in opposition to a patient's decision to forego treatment; when they are, those interests are seldom sufficient to outweigh a patient's unwillingness to undergo the suffering or burden of further treatment. Furthermore, provided that personal conscience is respected, the "rights" of health professionals are not jeopardized when they acquiese in decisions of patients to forego treatment. "Rather,...the prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment."[59] Finally, as a number of courts have recognized, the foregoing of life-sustaining treatment can usually be differentiated from the unreasonable self-destruction involved in suicide, which characteristically warrants state intervention.[60]

Regardless of how interests are weighed in specific cases, a decision to forego life-sustaining treatment has been firmly established as a Constitutionally protected right that can be overcome only by marshalling countervailing considerations of substantial weight.[61] In practice, these countervailing considerations are reflected in and implemented by the sanctions and procedures of criminal, civil, and administrative law.

Criminal law. Throughout the ages almost all cultures have regarded the protection of human life as a major aim of their legal systems. In the Anglo-American tradition, proscrip-

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[56] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 663, *cert. denied*, 429 U.S. 922 (1976).

[57] Note, *The Refusal of Life-Saving Treatment vs. The State's Interest in the Preservation of Life: A Clarification of the Interests at Stake*, 58 WASH. U.L.Q. 85 (Winter 1980).

[58] Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 424 (1977).

[59] *Id.* at 426.

[60] *See* pp. 37-38 *infra*.

[61] Not all cases, however, have relied upon a Constitutional claim. *See In re* Storar, 52 N.Y.2d 363, 420 N.E.2d 64 (1981), *rev'g In re* Storar, 433 N.Y.S.2d 388 (App. Div. 1980) and *modifying* Eichner v. Dillon, 426 N.Y.S.2d 517 (App. Div. 1980).

tions of homicide and suicide are fundamental components of the criminal law. Yet no such legal proscription is absolute. Self-defense, the defense of others, killing in the conduct of military activities, and capital punishment are among the well-established justifications and excuses for homicide.[62] Criminal law applies these same general norms to physicians and other health care professionals, not only in their capacity as ordinary citizens, but also in their professional capacities.

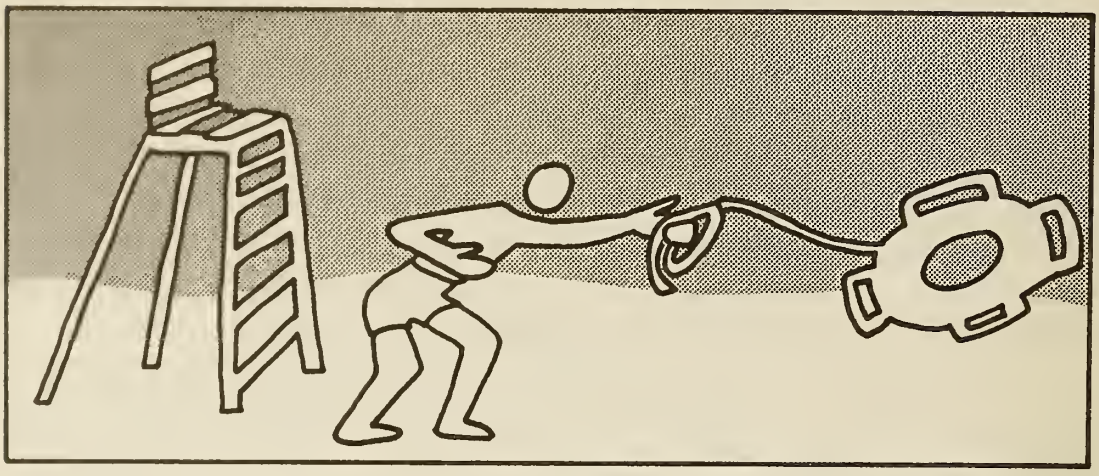
The criminal law confines people's freedom of action, in order to protect society, in ways that civil law does not. Although a patient's "informed consent" is sufficient authority in the civil law for a medical intervention, consent is never accepted as a defense to the crime of murder.[63] An individual who seeks death at the hands of another, regardless of the reason, does not confer immunity from prosecution on the one who takes the life, because the taking of innocent human life is seen as a wrong to the entire society, not just to the dead person. A physician's shooting or poisoning of a dying patient, even at the patient's request and from merciful motives, falls within the definition of murder.

In some situations the criminal law looks to other branches of the law to fill in the details of punishable conduct. The law ordinarily holds individuals liable only for the injurious consequences of their acts, not for the injurious consequences of omissions of action.[64] If someone throws into deep water a person who is known to be unable to swim and the nonswimmer then drowns, criminal and civil liability will be imposed. But if someone merely happens to be present when another is having obvious difficulty swimming in deep water, and if he or she is the only other person present and could rescue the drowning individual, that person ordinarily has no legal obligation to do so—although the failure to rescue may result in a less forgiving moral assessment. In the first case, the person "acts" and is liable; in the second, the person "omits" to act and is not liable. Of course, if a person takes on the responsibilities of a lifeguard, he or she is under a legal

[62] Wayne R. LaFave and Austin W. Scott, HANDBOOK ON CRIMINAL LAW, West Publishing Co., St. Paul, Minn. (1974) at 356-413.

[63] *Id.* at 408-09.

[64] George A. Oakes, *A Prosecutor's View of Treatment Decisions*, and Gregory R. Ginex, *A Prosecutor's View on Liability for Withholding or Withdrawing Medical Care: The Myth and the Reality*, in A. Edward Doudera and J. Douglas Peters, eds., LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS, AUPHA Press, Ann Arbor, Mich. (1982) at 194, 205; Jerry B. Wilson, DEATH BY DECISION, Westminister Press, Philadelphia (1975) at 148-155; LaFave and Scott, *supra* note 62, at 182; Model Penal Code § 2.01(3); Graham Hughes, CRIMINAL OMISSIONS, 67 Yale L. J. 590 (1958).



duty to act and an omission of this duty would become the basis of legal liability.[65]

Similarly, the recognized duty of physicians to treat patients with appropriate technologies and methods means that criminal sanctions may be imposed on a physician whose patient died because of the physician's failure to act in circumstances under which no liability would attach for nonphysicians. The *omission* of a duty to take protective action by someone obligated to do so, such as a physician or a parent, is regarded by the law in the same way that an *action* would be that led to the same result.

Despite the fact that there are rather rigid and seemingly ironclad prohibitions against intentionally taking the life of another, the administration of the criminal law allows a great deal of discretion, thereby permitting law to be tempered by justice, mercy—and even empathy.[66] Reported criminal prose-

[65] William L. Prosser, HANDBOOK OF THE LAW OF TORTS, West Publishing Co., St. Paul, Minn. (4th ed. 1971) at 338-43. The general rule of no duty to rescue has come under recurrent criticism by legal commentators. *See, e.g.*, Ernest J. Weinrib, *The Case for a Duty to Rescue*, 90 YALE L. J. 247 (1980).

[66] The ambivalent position of prosecutors in such cases is evident in the case of Woodrow Collums, a Texan convicted of the shooting death of his 72-year-old brother Jim, who suffered from Alzheimer's disease. Collums was sentenced to probation for ten years and required to spend time as a volunteer in a nursing home. The prosecutor in the case stated:

> Personally, emotionally, I am with Woodrow Collums, in that I have three brothers; we're very close, and I'm sure that if I were in the deathbed, or vice versa, I hope one of my brothers would end my suffering. But my position in court is as a prosecutor. And there, it's not that I'm going after Woodrow Collums personally. We have to protect the interest of potential victims out there.

Interview with Mike Sawyer on *60 Minutes*, CBS Network, New York (March 28, 1982) at 4 (transcript).

This analysis rests on the special role of physicians and on particular professional norms of acceptability that have gained social sanction (such as the difference between morphine, which can relieve pain, and strychnine, which can only cause death).[111] Part of acceptable behavior—from the medical as well as the ethical and legal standpoints—is for the physician to take into account all the foreseeable effects, not just the intended goals, in making recommendations and in administering treatment.[112] The degree of care and judgment exercised by the physician should therefore be guided not only by the technical question of whether pain can be relieved but also by the broader question of whether care providers are certain enough of the facts in this case, including the patient's priorities and subjective experience, to risk death in order to relieve suffering. If this can be answered affirmatively, there is no moral or legal objection to using the kinds and amounts of drugs necessary to relieve the patient's pain.

The Commission concludes that the distinction between the decisionmakers' "intending" a patient's death and their "merely foreseeing" that death will occur does not help in

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[111] These issues were addressed in a national survey conducted for the Commission by Louis Harris and Associates. Physicians, especially, distinguished between administering drugs to relieve pain, knowing that the dose might be lethal, and complying with a patient's wish to have his or her life ended. In the case of a patient in severe pain who had no hope of recovery and who asked to have the pain eased, knowing it might shorten life, 79% of the public and 82% of the physicians said it would be ethically permissible to administer drugs to relieve the pain even at the risk of shortening life. Furthermore, 84% of physicians said they would be likely to administer such drugs under these circumstances. When asked whether the law should allow such treatment, assuming the patient has requested the drug and understands the consequences, 71% of the public and 53% of the physicians said yes. When asked whether a physician would be right or wrong to comply with the wishes of a dying patient in severe pain who directly asks to have his or her life ended, 45% of the public said it would be right. Among physicians, however just 5% thought such compliance was ethically permissible, and a mere 2% said they would comply with such a request. 52% of the public thought the law should allow physicians to comply with a request for mercy killing, but only 26% of physicians thought so. Harris, *supra* note 39, at 217-62.

See also, John M. Ostheimer, *The Polls: Changing Attitudes Toward Euthanasia*, 44 PUB. OPINION Q. 123 (1980).

[112] This is a weighty responsibility, and one that correctly entails serious liabilities for the physician if wrongly carried out. Society does want risky treatments to be offered and suffering to be relieved but wants to circumscribe the authority to risk life or to relieve suffering in ways expected to shorten life. One way to do so is to impose penalities for negligent or otherwise unjustified actions that lead to death, and this is the role of legal proceedings for homicide and wrongful death.

separating unacceptable from acceptable actions that lead to death. But, as proved true of the distinctions already discussed, this does point to ethically and legally significant factors—here, the real and symbolic role traditionally assigned to physicians and other practitioners of the healing arts, who can be expected to have developed special sensitivity and skills regarding the judgments to be made, and who are an identifiable group that can be readily held accountable for serious error.[113] Furthermore, the acceptable treatment options that carry a risk of death are limited to those within the special expertise of health care professionals.

The highly valued traditional professional role is not undermined when a physician, with due care, employs a measure—whether radical surgery or medication to relieve pain—that could lead to the patient's death but that is reasonably likely to cure or relieve pain. The relevant distinction, then, is not really that death is forbidden as a means to relieve suffering but is sometimes acceptable if it is merely a foreseeable consequence. Rather, the moral issue is whether or not the decisionmakers have considered the full range of foreseeable effects, have knowingly accepted whatever risk of death is entailed, and have found the risk to be justified in light of the paucity and undesirability of other options.

Ordinary Versus Extraordinary Treatment. In many discussions and decisions about life-sustaining treatment, the distinction between ordinary and extraordinary (also termed "heroic" or "artificial") treatment plays an important role. In its origins within moral theology, the distinction was used to mark the difference between obligatory and nonobligatory care—ordinary care being obligatory for the patient to accept and others to provide, and extraordinary care being optional.[114]

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[113] Part of this endeavor is the development by professional groups of standards of practice that can be publicly discussed and modified. *See, e.g.*, the policies of various institutions and professional societies, Appendices C, G, H, and I, pp. 299, 459, 467, 493 *infra*; George P. Fletcher, *Prolonging Life: Some Legal Considerations*, in Edwin S. Shneidman ed., DEATH: CURRENT PERSPECTIVES, Mayfield Pub. Co., Palo Alto, Calif. (1976) at 484.

[114] James J. McCartney, *The Development of the Doctrine of Ordinary and Extraordinary Means of Preserving Life in Catholic Moral Theology Before the Karen Quinlan Case*, 47 LINACRE Q. 215 (1980). The first treatment of the topic was Soto's in 1582 when he pointed out that superiors could oblige their subjects under religious obedience to use medicine that could be taken without too much difficulty, but they could not oblige them to undergo excruciating pain because nobody is held to preserve life by such means. It was Banez who in 1595 introduced the terms "ordinary" and "extraordinary" into the discussion of the preservation of life. He stated that while it is reasonable to hold that a human being must conserve his or her life, one is not bound

It has also played a role in professional policy statements[115] and recent judicial decisions about life-sustaining treatment for incompetent patients.[116] As with the other terms discussed, defining and applying a distinction between ordinary and extraordinary treatment is both difficult and controversial and can lead to inconsistent results, which makes the terms of questionable value in the formulation of public policy in this area.

The meaning of the distinction. "Extraordinary" treatment has an unfortunate array of alternative meanings, as became obvious in an exchange that took place at a Commission hearing concerning a Florida case[117] involving the cessation of life-sustaining treatment at the request of a 76-year-old man dying of amyotrophic lateral sclerosis. The attending physician testified:

> I deal with respirators every day of my life. To me, this is not heroic. This is standard procedure....I have other patients who have run large corporations who have been on portable respirators. Other people who have been on them and have done quite well for as long as possible.[118]

By contrast, the trial judge who had decided that the respirator could be withdrawn told the Commission:

> Certainly there is no question legally that putting a hole in a man's trachea and inserting a mechanical respirator is extraordinary life-preserving means.

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to employ extraordinary means, but only to preserve life by nourishment and clothing common to all, by medicine common to all, and even through some ordinary and common pain or anguish (*dolorem*), but not through any extraordinary or horrible pain or anguish, nor by any undertakings (*sumptos*) extraordinarily disproportionate to one's state in life. Jose Janini, *La operation quirurgica, remedio ordinario*, 18 REVISTA ESPANOLA DE TEOLOGIA 335 (1958). For the current Catholic view, see note 132 *infra*.

[115] For example, a statement of the House of Delegates of the American Medical Association (December 1973) employs the ordinary/extraordinary language: "The cessation of the employment of extraordinary means to prolong life of the body when there is irrefutable evidence that biological death is imminent is the decision of the patient and/or his immediate family." Quoted in Benedict M. Ashley and Kevin D. O'Rourke, HEALTH CARE ETHICS: A THEOLOGICAL ANALYSIS, The Catholic Hospital Association, St. Louis, Missouri (1978) at 390.

[116] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 667, *cert. denied*, 429 U.S. 922 (1976); Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 424 (1977).

[117] Satz v. Perlmutter, 379 So.2d 359 (Fla. 1980).

[118] Testimony of Dr. Marshall J. Brumer, transcript of 8th meeting of the President's Commission (April 9, 1981) at 60-61.

> I do not think that the doctor would in candor allow that that is not an extraordinary means of preserving life.
>
> I understand that he deals with them every day, but in the sense of ordinary as against extraordinary, I believe it to be extraordinary.
>
> There was no question in this case, nobody ever raised the question that this mechanical respirator was not an extraordinary means of preserving life.[119]

The most natural understanding of the ordinary/extraordinary distinction is as the difference between common and unusual care, with those terms understood as applying to a patient in a particular condition. This interprets the distinction in a literal, statistical sense and, no doubt, is what some of its users intend. Related, though different, is the idea that ordinary care is simple and that extraordinary care is complex, elaborate, or artificial, or that it employs elaborate technology and/or great efforts or expense.[120] With either of these interpretations, for example, the use of antibiotics to fight a life-threatening infection would be considered ordinary treatment. On the statistical interpretation, a complex of resuscitation measures (including physical, chemical, and electrical means) might well be ordinary for a hospital patient, whereas on the technological interpretation, resuscitation would probably be considered extraordinary. Since both common/unusual and simple/complex exist on continuums with no precise dividing line, on either interpretation there will be borderline cases engendering disagreement about whether a particular treatment is ordinary or extraordinary.[121]

A different understanding of the distinction, one that has its origins in moral theology, inquires into the usefulness and burdensomeness of a treatment.[122] Here, too, disagreement

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[119] Testimony of Judge John G. Ferris, transcript of 8th meeting of the President's Commission (April 9, 1981) at 124.

[120] *See* Leslie Steven Rothenberg, *Down's Syndrome Babies: Decisions Not to Feed and the Letter from Washington*, 2 J. Calif. Perinatal Assoc. 73, 77-78 (Fall 1982).

[121] There are some even less understandable uses of the term "extraordinary." In defining the term "extraordinary life support systems or procedures," the formal response to a question directed by a county's attorney to the Attorney General of California states:

> We further understand the word "extraordinary" to distinguish those systems or procedures which are utilized on a continuing basis as necessary to the person's health. Thus we are not here concerned with those treatment measures employed to replace or assist a vital function on a continuing basis such as a heart transplant, a pacemaker, kidney dialysis, and the like.

65 Ops. Cal. Att'y Gen. 417, 418 (1982), *reprinted in* Appendix I, pp. 537-45 *infra*.

[122] The ordinary-extraordinary distinction has had special importance

persists about which outcomes are considered useful or burdensome.[123] Without entering into the complexity of these debates, the Commission notes that any interpretation of the ordinary/extraordinary distinction in terms of usefulness and burdensomeness to an individual patient has an important advantage over the common/unusual or simple/complex interpretations in that judgments about usefulness and burdensomeness rest on morally important differences.

Despite the fact that the distinction between what is ordinary and what is extraordinary is hazy and variably defined, several courts have employed the terms in discussing cases involving the cessation of life-sustaining treatment of incompetent patients. In some cases, the courts used these terms because they were part of the patient's religious tradition.[124] In other cases, the terms have been used to

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and a special meaning within Catholic moral theology. The distinction dates back several centuries, but much of its prominence stems from its use by Pope Pius XII in a 1957 address in which he stated: "But normally one is held to use only ordinary means—according to circumstances of persons, places, times, and culture—means that do not involve any grave burden for oneself or another." *The Prolongation of Life*, 4 THE POPE SPEAKS, Vatican City (1958) at 393, 395-96.

The distinction is here employed within a general theological view of human life as a gift from God that should not be deliberately destroyed by man. As such, it serves to clarify and qualify the absolute obligation to refrain from deliberately taking innocent human life, in light of medical treatments capable of extending a patient's life only by imposing grave burdens on the patient or others. The obligation to sustain life was extended to accepting ordinary, beneficial medical therapies, but not to require extraordinary therapies. For interpretations of the distinction within the Catholic tradition, see Richard A. McCormick, *To Save or Let Die: The Dilemma of Modern Medicine*, 229 J.A.M.A. 172 (1974); Edwin F. Healy, MEDICAL ETHICS, Loyola Univ. Press, Chicago (1956); The Linacre Centre, *Prolongation of Life, Paper 3: Ordinary and Extraordinary Means of Prolonging Life*, LINACRE CENTRE, London (1979).

[123] Disagreement persists about which outcomes should count as being useful or burdensome (for example, whether the life that is sustained can itself be burdensome or only the treatment; whether financial costs are relevant burdens; whether evaluations can be specified independent of, or only in light of, a particular patient's circumstances and values; and especially whether benefits and burdens only to the patient or also to others such as the patient's family are relevant). *See, e.g.*, McCartney, *supra* note 114.

[124] For example, in *Quinlan*, the New Jersey Supreme Court dealt with the "Catholic view" only insofar as it related to the "conscience, motivation, and purpose of the intended guardian.., and not as a precedent in terms of civil law." *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 660, *cert. denied*, 429 U.S. 922 (1976). Likewise the Eichner court admitted evidence as to Catholic teachings as "probative of the basis for Brother Fox's state in mind concerning this question." Eichner v.

characterize treatments as being required or permissibly foregone. For example, the New Jersey Supreme Court in the *Quinlan* case recognized a distinction based on the possible benefit to the individual patient:

> One would have to think that the use of the same respirator or life support could be considered "ordinary" in the context of the possibly curable patient but "extraordinary" in the context of the forced sustaining by cardio-respiratory processes of an irreversibly doomed patient.[125]

Likewise, the Massachusetts Supreme Judicial Court quoted an article in a medical journal concerning the proposition that ordinary treatment could become extraordinary when applied in the context of a patient for whom there is no hope:

> We should not use *extraordinary* means of prolonging life or its semblance when, after careful consideration, consultation and application of the most well conceived therapy it becomes apparent that there is no hope for the recovery of the patient. Recovery should not be defined simply as the ability to remain alive; it should mean life without intolerable suffering.[126]

Even if the patient or a designated surrogate is held to be under no obligation to accept "extraordinary" care, there still remains the perplexing issue about what constitutes the dividing line between the two. The courts have most often faced the question of what constitutes "ordinary" care in cases when the respirator was the medical intervention at issue. Generally the courts have recognized, in the words of one judge, that "the act of turning off the respirator is the

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Dillon, 426 N.Y.S.2d 517, 547 (App. Div. 1980), *modified in, In re* Storar, 52 N.Y.2d 363, 420 N.E.2d 64 (1981). The Cruse case also admitted expert testimony on Catholic teaching as evidence of the parents' "good faith" in seeking removal of a respirator. *In re* Benjamin Cruse Nos. J9 14419 and P6 45318, slip op. at 4 (Los Angeles Sup. Ct., Feb. 15, 1979).

[125] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 668, *cert. denied*, 429 U.S. 922 (1976).

[126] Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 424 (1977) (citing Howard P. Lewis, *Machine Medicine and Its Relation to the Fatally Ill*, 206 J.A.M.A. 387 (1968), citations omitted). The *Dinnerstein* court cited the same source and also relied upon fatal illness as a distinguishing factor.

> The essence of this distinction in defining the medical role is to draw the sometimes subtle distinction between those situations in which the withholding of extraordinary measures may be viewed as allowing the disease to take its natural course and those in which the same actions may be deemed to have been the cause of death.

In re Dinnerstein, 380 N.E.2d 134, 137 n.7 (Mass. App. Ct. 1978).

termination of an optional, extraordinary medical procedure which will allow nature to take its course."[127]

For many, the harder questions lie in less dramatic interventions, including the use of artificial feeding and antibiotics. In one criminal case involving whether the defendant's robbery and assault killed his victim or whether she died because life-supporting treatments were later withdrawn after severe brain injury was confirmed, the court held that "heroic" (and unnecessary) measures included "infusion of drugs in order to reduce the pressure in the head when there was no obvious response to those measures of therapy."[128] In another case, in which a patient's refusal of an amputation to prevent death from gangrene was overridden, antibiotics were described by the physician "as heroic measures, meaning quantities in highly unusual amounts risking iatrogenic disease in treating gangrene."[129] Here the assessment, in addition to relying on "benefits," also seems to rely to some degree upon the risk and invasiveness of the intervention. One court did begin to get at the scope of the questions underlying the ordinary/extraordinary distinction. Faced with the question of treatment withdrawal for a permanently unconscious automobile accident victim, the Delaware Supreme Court asked what might constitute life-sustaining measures for a person who has been comatose for many months:

> Are "medicines" a part of such life-sustaining systems? If so, which medicines? Is food or nourishment a part of such life-sustaining systems? If so, to what extent? What extraordinary measures (or equipment) are a part of such systems? What measures (or equipment) are regarded by the medical profession as not extraordinary under the circumstances? What ordinary equipment is used? How is a respirator regarded in this context?[130]

The moral significance of the distinction. Because of the varied meanings of the distinction, whether or not it has moral significance depends upon the specific meaning assigned to it. The Commission believes there is no basis for holding that whether a treatment is common or unusual, or whether it is simple or complex, is in itself significant to a moral analysis of whether the treatment is warranted or obligatory. An unusual treatment may have a lower success rate than a common one; if so, it is the lower success rate rather than the unusualness of the procedure that is relevant to evaluating the therapy.

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[127] *In re* Benjamin Cruse, Nos. J9 14419 and P6 45318, slip op. at 6-7 (Los Angeles Sup. Court, Feb. 15, 1979).

[128] Parker v. U.S., 406 A.2d 1275, 1279 n.1 (D.C. Ct. App., 1979).

[129] State Department of Human Services v. Northern, 563 S.W.2d 197 (Tenn. Ct. App. 1978).

[130] Severns v. Wilmington Medical Center, Inc., 421 A.2d 1334, 1349 (Del. 1980).

Likewise, a complex, technological treatment may be costlier than a simple one, and this difference may be relevant to the desirability of the therapy. A patient may choose a complex therapy and shun a simple one, and the patient's choice is always relevant to the moral obligation to provide the therapy.

If the ordinary/extraordinary distinction is understood in terms of the usefulness and burdensomeness of a particular therapy, however, the distinction does have moral significance. When a treatment is deemed extraordinary because it is too burdensome for a particular patient, the individual (or a surrogate) may appropriately decide not to undertake it. The reasonableness of this is evident—a patient should not have to undergo life-prolonging treatment without consideration of the burdens that the treatment would impose. Of course, whether a treatment is warranted depends on its usefulness or benefits as well. Whether serious burdens of treatment (for example, the side effects of chemotherapy treatments for cancer) are worth enduring obviously depends on the expected benefits—how long the treatment will extend life, and under what conditions. Usefulness might be understood as mere extension of life, no matter what the conditions of that life. But so long as mere biological existence is not considered the *only* value, patients may want to take the nature of that additional life into account as well.[131]

This line of reasoning suggests that extraordinary treatment is that which, in the patient's view, entails significantly greater burdens than benefits and is therefore undesirable and not obligatory, while ordinary treatment is that which, in the patient's view, produces greater benefits than burdens and is therefore reasonably desirable and undertaken. The claim, then, that the treatment is extraordinary is more of an expression of the conclusion than a justification for it.

The role of the distinction in public policy. Despite its long history of frequent use, the distinction between ordinary and extraordinary treatments has now become so confused that its continued use in the formulation of public policy is no longer desirable.[132] Although those who share a common

[131] Pope Pius XII acknowledged this in his statement that "Life, health, all temporal activities are in fact subordinate to spiritual ends." *The Prolongation of Life, supra* note 122. *See also* Richard McCormick, *The Quality of Life, the Sanctity of Life*, 8 HASTINGS CTR. REP. 30 (Feb. 1978); Robert M. Veatch, DEATH, DYING AND THE BIOLOGICAL REVOLUTION, Yale Univ. Press, New Haven, Conn. (1976) at 77.

[132] The Commission is not the first to have come to this conclusion. *See e.g.*: "You do not need to puzzle for very long over the categorical distinction between 'ordinary' and 'extraordinary' means of saving life. By that I mean those terms as classes or categories of treatment are no longer useful." Paul Ramsey, ETHICS AT THE EDGE OF LIFE, Yale Univ. Press, New Haven, Conn. (1978) at 153. The overuse and misuse of the term has led the Vatican to question the usefulness of the

understanding of its meaning may still find it helpful in counseling situations, the Commission believes that it is better for those involved in the difficult task of establishing policies and guidelines in the area of treatment decisions to avoid employing these phrases. Clarity and understanding in this area will be enhanced if laws, judicial opinions, regulations, and medical policies speak instead in terms of the proportionate benefit and burdens of treatment as viewed by particular patients. With the reasoning thus clearly articulated, patients will be better able to understand the moral significance of the options and to choose accordingly.

Conclusions

Good decisionmaking about life-sustaining treatments depends upon the same processes of shared decisionmaking that should be a part of health care in general. The hallmark of an ethically sound process is always that it enables competent and informed patients to reach voluntary decisions about care. With patients who may die, care givers need special skills and sensitivities if the process is to succeed.

A number of constraints on the range of acceptable decisions about life-sustaining treatment have been suggested. They are often presented in the form of dichotomies: an omission of treatment that causes death is acceptable whereas an action that causes death is not; withholding treatment is acceptable whereas withdrawing existing treatment is not; extraordinary treatment may be foregone but ordinary treatment may not; a person is permitted to do something knowing that it will cause death but may not aim to kill. The Commission has concluded that none of these dichotomies should be used to prohibit choosing a course of conduct that falls within the societally defined scope of ethical medical practice. Instead, the Commission has found that a decision to forego treatment is ethically acceptable when it has been made by suitably qualified decisionmakers who have found the risk of death to be justified in light of all the circumstances. Furthermore, the Commission has found that nothing in current law precludes ethically sound decisonmaking. Neither criminal nor civil law—if properly interpreted and applied by lawyers, judges, health care providers, and the general public—forces patients to undergo procedures that will increase their suffer-

terminology. The *Declaration on Euthanasia* proposes substituting "proportionate" and "disproportionate" for the more traditional, but perhaps outmoded, "ordinary/extraordinary." Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (June 26, 1980), *reprinted in* Appendix C, pp. 300-307 *infra*.

ing when they wish to avoid this by foregoing life-sustaining treatment.

Since these conclusions recognize the importance of societally defined roles, health care professionals, individually and through their professional associations, will need to become more active in creating, explaining, and justifying their standards regarding appropriate professional roles. Within presently accepted definitions, it is already apparent that health care professionals may provide treatment to relieve the symptoms of dying patients even when that treatment entails substantial risks of causing an earlier death. The Commission has also found no particular treatments—including such "ordinary" hospital interventions as parenteral nutrition or hydration, antibiotics, and transfusions—to be universally warranted and thus obligatory for a patient to accept. Nevertheless, a decision to forego particular life-sustaining treatments is not a ground to withdraw all care—nor should care givers treat it in this way, especially when care is needed to ensure the patient's comfort, dignity, and self-determination.

Additional Constraints on a Patient's Decision

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In actual decisionmaking about life-sustaining treatment, various personal and institutional influences and constraints restrict reliance upon the voluntary choice of informed, competent patients. First, other people who become involved may find that a particular choice conflicts with their own values and hence be unwilling to act on a particular decision, which may place pressures on a patient. Second, society in various ways may restrict access to some care for some people in order to allocate scarce resources equitably. Third, the rules and practices—and indeed, the whole ethos—of health care institutions can profoundly affect patients' choices.

Other People Involved in Patients' Decisions

The people—family and health care professionals—whom patients rely on to provide care and to carry out their decisions influence choices in two ways: first, by their willingness to be agents to implement a particular choice; and, second, by their response to unexpected, especially iatrogenic, complications of treatment that require rapid decisionmaking on behalf of a patient.

Acting as Agent for a Patient's Decision. Nearly every decision about life-sustaining treatment involves people other than the patient. Even competent patients making voluntary and informed choices must usually rely on health care personnel to act on those choices and often also need help from family members.

Those who act as agents for patients' decisions will have their own decisions to make. A patient's choice need not be the one that the agent would make under similar circumstances; it need only be seen as an appropriate and reasonable one for this patient. When there is some question on this point, a

person acting as an agent is justified in carefully evaluating the patient's competence, voluntariness, and comprehension, as well as the reliability of the information presented. Yet several other issues are raised by the fact that a patient's decision is to be carried out by another person.

First, the intention of a patient who is capable of carrying out his or her own decision independently is usually expressed directly through the action. When such decisions must be communicated to others, however, they can be seriously misinterpreted. Communication is much more than the mere transmittal of factual information. It conveys the mood and orientation of a patient and provides a means for that person to manipulate and test the environment. These considerations preclude the automatic acceptance of a patient's statements at face value, especially when they are against life-sustaining therapy.[1] Instead, those asked to act (or to refrain from acting) must look carefully for hidden meanings and nonverbal communication that might give a more accurate reading of a patient's declarations. Without any one person intending it, each participant in this decisionmaking process may "choose" according to what is perceived as the outcome desired by the other participants—not according to his or her own values and desires—and each other person may, in turn, be doing the same. Moreover, agents must be cautious not to let their own values dictate their responses, thereby systematically discounting a patient's intentions and explicit declarations.

Second, patients who cannot act on their own decisions lose an important protection—the reluctance individuals ordinarily feel in actually taking steps that will lead to their own demise. Some patients who seem satisfied with continuing artificial life-support stop treatment when they gain control of the situation; conversely, some who claim to want a life-sustaining therapy stopped do not do so when they get the chance.[2] Consequently, anyone who acts for a patient in this regard should carefully consider whether he or she is unduly affecting the patient's decision by being too willing to bear the responsibility for the actual action.

By having to involve others, a patient also risks the loss of privacy. Often a decision to forego treatment will be controver-

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[1] *See* pp. 48-49 *supra*. *See also* David L. Jackson and Stuart Youngner, *Patient Autonomy and 'Death with Dignity': Some Clinical Caveats*, 301 NEW ENG. J. MED. 404 (1979); Ned H. Cassem, *When to Disconnect the Respirator*, 9 PSYCHIATRIC ANN. 84 (1979); Ruth Faden and Alan Faden, *False Belief and the Refusal of Medical Treatment*, 3 J. MED. ETHICS 133 (1977).

[2] Robert B. White and H. Tristram Engelhardt, Jr., *Case Study: A Demand to Die*, 5 HASTINGS CTR. REP. 9 (June 1975); *One of our Newest M.D.'s is a Paraplegic Who Once Sued For the Right to Die*, 3 THE BIOETHICS LETTER 3 (Dec. 1982).

sial among some family members, acquaintances, and others. A patient may well want to exercise his or her prerogative to limit the disclosures made to various people. Such a prohibition, however, can place burdens upon those involved in implementing the decision. These difficulties are usually satisfactorily resolved by the good-faith efforts of all involved. When they are not resolved and when a review of a patient's decision is needed, institutional bodies and the courts will have to take special precautions to preserve privacy interests.[3]

The law regarding decisions about life-sustaining treatment is not clear or uniform in its application.[4] Those involved in carrying out a patient's or a surrogate's decision will want to assess their potential civil or criminal liability and reduce it in a responsible fashion. There is little reason to believe that liability would arise for actions taken on the basis of the decisions of competent patients that are arrived at in an appropriate fashion. Detailed records of the decisionmaking process would often be strong evidence of good medical practice. Liability could attach, however, to compliance with a competent patient's decision—whether it is to undertake or to forego therapy—if the decision was the result of a seriously deficient decisionmaking process.[5] Refusing to comply with a patient's request for termination of treatment out of fear of potential liability is a decision that, for now, will have to be made on a case-by-case basis.[6] Yet it would be most unfortu-

[3] Many of the protracted proceedings held to determine the legal propriety of decisions to forego life-sustaining treatment have been attended by considerable publicity, compounding already tragic situations for families involved. In the Earle Spring case, for example, a nursing home administrator allowed right-to-life advocates to interview the patient without his guardian's consent; the interview was subsequently published in a local newspaper. His widow sued the nursing home and four nurses and was awarded $2.58 million, including $2.5 million in damages for violation of the state's fair information practices act. Defense arguments that Spring had become a public figure did not succeed. *Home Loses 'Right to Die' Case*, AM. MED. NEWS, Dec. 10, 1982, at 20. Exactly what privacy protections may be warranted is not yet clear. There may need to be ways of protecting parts of the patient's chart or, sometimes, even the patient's identity. *See also* pp. 167-68 *infra*.

[4] David W. Meyers, MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING, Lawyers Co-Operative Publishing Co., Rochester, New York (1981); A. M. Capron, *Euthanasia*, in 2 ENCYCLOPEDIA OF CRIME AND JUSTICE, Macmillan-Free Press, New York (forthcoming). *See* pp. 30-41 *supra* and pp. 153-60 *infra*.

[5] *See* pp. 32-34 *supra* .

[6] The situation can be highly influenced by the particular proclivities of local prosecutors and their perceptions of the political climate. For example, an assistant District Attorney in New York informed a large gathering of physicians and attorneys:

nate if this fear prevented physicians and other health care professionals from acting in the manner they believe is appropriate, medically and ethically, in light of a patient's wishes.

Finally, for reasons of personal commitment, value judgment, or professional role, competent patients will sometimes be unable to secure the cooperation of others to implement their informed, voluntary decisions.[7] The resolution of such issues will entail counseling and compromise. In general, either patient or physician (with adequate notice) can withdraw from a relationship, and no one may forcibly undertake or continue interventions over the objections of competent patients or qualified surrogates.[8] However, each party can and often should seek advice within the guidelines of legitimate professional practice and institutional policy—or, where necessary, judicial decree—to resolve any discord.

Responding to Complications of Treatment. A particularly troubling, albeit rare, situation arises when a patient who is dying or who has refused specific life-sustaining treatment encounters a life-threatening complication (through an inadvertent or unfortunate side effect) of otherwise warranted therapy. For example, a rather routine therapy, perhaps an antibiotic for an infected tooth, might cause a massive allergic reaction that will be fatal in minutes without resuscitation. This patient may have already indicated a wish not to be revived if an unexpected heart attack were to lead to the same situation; and, given the opportunity to choose a course of action, he or she might even choose not to be resuscitated in this situation. Sometimes an account of the changed situation from the patient's perspective alone would hold that the complication

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> As things stand now, withdrawal of life support is homicide....(Although) [t]he majority would not bring charges because they felt no jury would convict a doctor who acted out of humanitarian motives....[t]here are DA's in this state anxious to pursue such a charge. One told me he would see how many are enrolled in the Right to Life Party in his county. And he'd go from there.

David Zinman, *Critical Question of Life/Death*, NEWSDAY, Oct. 28, 1981, at 2 (quoting Robert L. Adams).

[7] Francis D. Moore, *Therapeutic Innovation—Ethical Boundaries in the Initial Clinical Trials of New Drugs and Surgical Procedures*, 8 DAEDALUS 509 (1969); Paul Heller, *Informed Consent and the Old-Fashioned Conscience of the Physician-Investigator*, 20 PERSPECTIVES IN BIOLOGY & MED. 434 (1977); Yashar Hirshaut and David Bleich, *Case Study: Choosing a Therapy When Doctors Disagree*, 5 HASTINGS CTR. REP. 19 (April 1975); W. Cole Durham, Mary Anne Q. Wood, and Spencer J. Condie, *Accommodation of Conscientious Objection to Abortion: A Case Study of the Nursing Profession*, 1982 B.Y.U. L. REV. 253.

[8] *See* pp. 43-45 *supra*.

should not be treated, either because the way the patient dies is preferable to the alternatives that he or she otherwise faced or because the necessary ameliorative treatment is intolerable to the patient. Yet two problems with such a decision remain: first, the patient was most likely not asked about this rare and unpredictable complication whose treatment, though dramatic, is most often completely successful; and, second, the professionals who administered the antibiotic will feel responsible for the patient's death in a way they never would have for death from a heart attack.

All such situations will be very difficult, especially if the patient's wishes are uncertain. Each time this conflict arises, the physician in charge faces a dilemma: not wanting to violate a patient's wishes, especially when doing so may well harm the patient, yet not wanting to fail to rescue someone from a death produced by a medical treatment. Public policy is caught in the same dilemma. The motivations for both courses are laudable, yet adopting either course of action as the standard does violence to the values that underlie the other.

The Commission does not propose any uniform resolution of this tension; rather, the resolution in specific cases will depend on the prudent judgment of the people involved in the case. The decision should, as much as possible, be the one the patient would have made. If that is impossible to determine, the presumption in favor of life should tilt toward administering the needed treatment. Again, it would be very unfortunate if the hypothetical threat of liability were to become a major factor in deterring an agent from a course that he or she would otherwise follow.

Constraints Imposed to Achieve Equitable Allocation of Resources

Most patients' decisions about life-sustaining therapy involve the use of societal resources and thus have consequences for many other people. How and to what extent should the decisionmaking process take this into account?

Life-sustaining therapies can be very expensive. Even when a therapy itself is not expensive (such as antibiotic therapy for an infection or temporary intravenous feeding), the total expense of maintaining a patient who would not survive without the therapy can be substantial. Very few patients pay directly for health care. Instead, costs are routinely spread over large groups of people through public and private mechanisms, including private health insurance, government financing programs such as Medicare and Medicaid, and the

provision of free care by governmental and charitable institutions.[9]

The equity issues raised by public and private cost-spreading often seem to differ. A person with private insurance purchased a contract to be reimbursed for the costs of care if the need arises. Since premiums are based on probable use (plus profits and administrative costs), at least for the group of insured persons as a whole, a policyholder can be said to bear the expected cost through payment of premiums. Public programs, however, are supported by taxes that are unrelated to each person's probable use. In fact, these programs are usually explicitly redistributive (wealthier citizens contribute more than the poor, who are often the major beneficiaries). Thus, in public programs it is clearer that others have a reason to be concerned about an individual patient's decision.

In both public payment programs and private insurance, however, an individual's decision about the use of care does have significant effects on the costs borne by others. The resultant potential for conflict of interests could be avoided if people were made to bear all costs directly. But people buy health insurance and support government health care programs partly because they fear that some day they will need clearly beneficial care and be unable to afford it—and because their hearts go out to others who find themselves in that position. Making everyone bear the cost directly is unacceptable because it would deprive people of highly valued personal security and because people do not want a society in which individuals die or suffer substantial harm because they cannot afford necessary health care.

On the other hand, allowing decisions about life-sustaining care to be made with total disregard for the costs they impose on others has equally serious implications. Enormous expenditures may be made for very limited benefits, such as sustaining a painful and burdened life for an individual who has little or no capacity to enjoy it. When medical resources are used without concern for cost, the pattern of expenditures that results does not accurately reflect societal values because the pursuit of other goals remains constrained by costs.

Are there ethically acceptable alternatives to these extremes? The concept of access to an adequate level of health care without excessive burdens set forth in the Commission's

[9] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Securing Access to Health Care, U.S. Government Printing Office, Washington (1983) at 90-108.

report on equity in access to health care provides a framework for responsibly resolving this difficult question.[10] The Commission held it appropriate to take both the significance of the care to the individual and its cost into account in deciding what constitutes adequate care and what burdens are excessive. Society is not obligated to provide every intervention that the patient or provider believe might be beneficial.

Undeniably, the role that health care plays in sustaining life is very important, but the fact that a therapy is life-sustaining does not automatically create an obligation to provide it. Rather, the therapy must offer benefits proportionate to the costs—financial and otherwise[11]—and the benefit provided must be comparable to that provided other patients in similar circumstances. For example, care for chronic conditions that interfere with the enjoyment of life (for example, arthritis) might be given greater importance than care that merely sustains a very limited existence (such as artificial support of major organ systems for patients who are already bedridden and in pain).

Though it is acceptable in principle—and probably unavoidable in practice—to consider cost in deciding about health care, explicitly restricting treatment decisions on financial grounds poses significant dangers. Because people vary greatly in the value they attach to particular forms of life-extension, uniform rules based on objective measures of disease would create unacceptable consequences in some cases. For example, people differ in their attitudes about life on a respirator—some treasure each additional minute of life, whereas others find the treatment intolerable. And individual views change with time and circumstances; a patient may want very vigorous treatment until a family member who lives far away arrives or a grandchild is born, while finding the same treatment unwarranted thereafter.[12]

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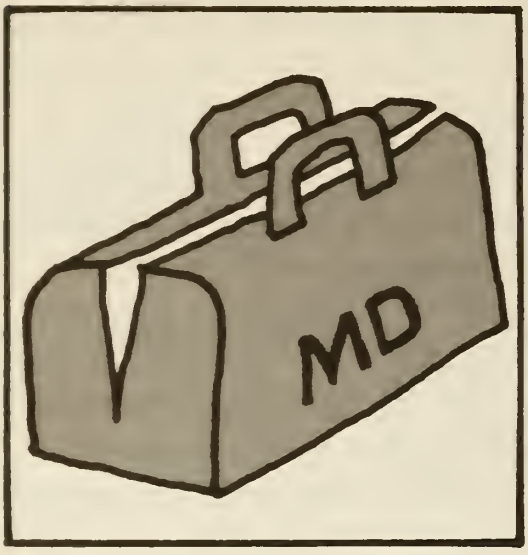
[10] *Id.* at 11-47. *See also* Testimonies of Norman Daniels and David Gautier, transcript of 13th meeting of the President's Commission (Oct. 22, 1981) at 27-30, 35-37.

[11] The Catholic Church, for example, explicitly includes expense as part of the assessment of whether a treatment is "disproportionate" and thus not obligatory. Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*, Vatican City (1980), *reprinted in* Appendix C, pp. 300-07 *infra*.

[12] Private financial arrangements might reasonably encourage consideration of cost while allowing for individual values. For example, the provision of contracts (by insurance companies or other prepayment arrangements) that have different kinds of exclusions and limits might be one way of letting people make their own trade-offs between lower premiums, better coverage of conditions that are not life-threatening, and coverage of certain life-sustaining therapies. In advance, however, it is difficult for people to make such trade-offs reasonably. Decisions about such contracts are often uninformed or severely



Beyond the unfairness of inappropriate application of the rules, there is a danger that rules that denied access to life-prolonging care would be seen to pass a value judgment about the patients as individuals and about their social worth. This is a particular problem in public programs for the poor and the handicapped; if the measures to sustain life under programs like Medicare and Medicaid are much more severely constrained than those available to citizens generally, perceptions of unjustified discrimination and a "devaluation" of the lives of those affected might arise.

Finally, the judgment and cooperation of physicians are crucial for the functioning of a system in which such constraints are imposed. But physicians have few incentives to adopt any role other than that of strong advocates on behalf of each patient. Both their professional ethos and the legal constraints within which they work provide powerful disincentives for a role as allocator of resources. Thus cost constraints that are externally imposed—rather than arising from the profession's ongoing reevaluation of the appropriateness of certain attitudes and practices—are more likely to induce circumvention than compliance on the part of physicians.

There are few instances in which there is a strong societal consensus that cost is so high that care should not be given, even when patients greatly desire it. In many societies, these issues must be faced head-on. Hard choices must be made about the level of life-sustaining care to provide, given the very limited resources available in those societies. In this country, however, discussions of the need to control health care costs—which are occurring with increasing frequency—often are stymied because they first turn to examples involving life-sustaining treatment in which the care does provide significant benefit to the patient but is very costly. The suggestion seems to be that any serious attempt at cost-containment must begin with restrictions on this sort of care. Actually, this would seem to be a poor place to begin. The limitations on access to life-sustaining care that are acceptable in other societies would

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constrained by a person's financial or employment situation or by the limited range of alternatives offered. The difficulties are even more severe in the case of public programs in which there is even greater tension between the need for similar treatment of similar cases, for the sake of fairness, and the need to allow for individual variations to reflect differing deeply held values.

probably be found unacceptable in this country. The United States can reasonably afford to include many forms of labor-intensive and high-technology life-support in its definition of adequate care.

In addition, a myriad of "small-ticket" tests and treatments probably account for more expenditures with disproportionately small payoffs than more dramatic forms of treatment do.[13] If cost-control incentives could be increased throughout the existing health care system, a substantial amount of care could be eliminated without substantial consequences for health or life. Reports by the Food and Drug Administration suggest, for example, that about one-third of the 75 million chest X-rays done in 1980 (at a cost of nearly $2 billion) were unnecessary in that before they were taken it was clear that they were unlikely either to detect disease or affect its outcome.[14] Similarly, although cardiac pacemakers can make the difference between life and death, a recent study suggests that their use in cases in which they are not medically indicated may be adding as much as $280 million annually to the nation's health care expenditures.[15] At least 25% of "respiratory care" (treatments and tests for breathing now costing $5 billion annually) is reportedly unnecessary.[16] Numerous other examples of questionable health care expenditures have been documented.[17]

Even when treatment is life-sustaining, in many cases patients and physicians agree that the patient's prognosis makes the treatment of so little benefit that it is not worth pursuing. If decisionmaking about life-saving treatment could be improved along the lines in this Report—by being freed from misunderstanding about the dictates of law and morality—considerable savings might also result, not from explicit limitations on costs but as a consequence of better decisionmaking that took individual facts and values into account in each case.

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[13] Thomas W. Moloney and David E. Rogers, *Medical Technology—A Different View of the Contentious Debate Over Costs*, 301 NEW ENG. J. MED. 1413 (1979).

[14] Jeanne Kassler, *Routine Use of Chest X-Ray is Under Attack*, N.Y. TIMES, Aug. 10, 1982, at C-1.

[15] Howie Kurtz, *25% of Pacemakers Unnecessary*, WASH. POST, July 8, 1982, at A-6 (reporting joint study by the Health Research Group and Dr. Peter R. Kowey); Philip J. Hilts, *Probe Finds Kickback on Pacemakers*, WASH. POST, Sept. 5, 1982, at A-1 (describing investigation into pacemaker industry by Department of Health and Human Services).

[16] Victor Cohn, *Health Insurers Would Stifle Some Respiratory Outlays*, WASH. POST, Oct. 21, 1982, at A-3 (quoting Dr. Marvin Shapiro, Chairman of the Board of Blue Cross/Blue Shield).

[17] SECURING ACCESS TO HEALTH CARE, *supra* note 9, at 185-90.

Although society might be justified in limiting access for some very costly forms of life-sustaining treatment, the Commission does not believe that it would now be wise to focus decisions about such therapy on the issue of cost-containment. Nor should discussions of cost-containment begin with consideration of life-sustaining treatments.[18] If potential benefits must be foregone, they should first be in areas that allow more dispassionate reflection and opportunity to rectify errors. Where resource allocation policies do limit the availability of life-sustaining therapies, steps should be taken to help patients understand these policies and the reasons they were enacted. This will help patients accept the policies or see the need to seek alternative ways to obtain the desired care. More stringent constraints on the availability of life-sustaining therapies should not be imposed on those who are dependent on public programs than would be found acceptable by Americans who pay for their health care through private insurance coverage.[19]

Meanwhile, efforts should certainly be made to educate the public about the connection between reasonable limits on the use of care, freedom from the fear of overwhelming health care costs, and the ability to obtain care that is of great importance to personal well-being. In the long run, a societal consensus about access to health care, including life-sustaining care, is needed. Rather than beginning with restrictions on life-sustaining care, however, it would be better to develop principles for equitable and acceptable limits on the use of health care generally, and then to apply those principles to issues at the end of life.[20]

Institutional Rules and Practices

Three-quarters of the deaths in the United States occur in a hospital or long-term care facility.[21] Even if death occurs at

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[18] Paul Ramsey, THE PATIENT AS PERSON, Yale University Press, New Haven, Conn. (1970) at 117-18; James F. Childress, *Who Shall Live When Not All Can Live*?, 43 SOUNDINGS 339 (1970); Guido Calabresi and Philip Bobbitt, TRAGIC CHOICES, W.W. Norton, New York (1978).

[19] SECURING ACCESS TO HEALTH CARE, *supra* note 9, at 5-6.

[20] Since life-sustaining care is a matter of particular importance with older patients, whose care is largely paid for under public programs (particularly Medicare and Medicaid), restrictions on marginally beneficial use of funds must avoid a real or perceived conflict between the role of the government as articulator of rights and responsibilities (especially regarding the protection of human life) and its role as allocator of collective financial resources. For this reason, too, the Commission hopes that the conclusions and recommendations contained in this Report will stimulate the establishment of good decisionmaking policies by public and private bodies now, before the current debates on cost-containment are resolved.

[21] In a review of 35,381 cancer deaths in Cuyahoga County, Ohio, from

home, treatment of many illnesses, including the leading causes of death (cancer, stroke, trauma, and heart disease), usually involves a period in a health care institution. Thus, the structure, rules, and general character of these institutions have important—though seldom considered—implications for patients' decisionmaking.[22]

Professional traditions and educational norms, societal incentives and disincentives (such as reimbursement rules), and the dictates of administrative convenience and professional needs help to shape the character of each institution, often without particular attention being paid to their effects on decisionmaking by or on behalf of patients. The choices available to patients are affected not only by the ethos of the institution they are in but also by the range of available alternatives to being in that institution. The effects may be so indirect and unstated that patients never really have an opportunity to understand the true impact of a decision to be admitted to a particular health care institution.[23]

1957-1974, 65% of the people died in hospitals, 15% in nursing homes, and 20% at home. Arthur Flynn, *Where Do Cancer Patients Die*?, 5 J. Community Health 126 (Winter 1979). *See also* John M. Hinton, *Comparison of Places and Policies for Terminal Care*, 1 Lancet 29 (1979); Roger Pritchard, *Dying: Some Issues and Problems*, 164 Annals N.Y. Acad. Sci. 707 (1969).

Hospitals and nursing homes are not the only institutional settings for such decisions—questions about foregoing life-sustaining treatment have also arisen in such settings as mental institutions and prisons. *See, e.g.*, Commissioner of Corrections v. Meyers, 399 N.E. 2d 452 (Mass. App. 1979) (dialysis ordered over objection of prisoner noting state interest in preservation of life and orderly operation of penal facilities). *But see* Zant v. Prevatte, 248 Ga. 832, 286 S.E.2d 715 (1982) (prisoner's right to privacy allows refusal of force-feeding during hunger strike).

[22] Robert L. Kane and Rosalie A. Kane, *Care of the Aged: Old Problems in Need of New Solutions*, in Philip H. Abelson, ed., Health Care: Regulation Economics, Ethics, Practice, American Association for the Advancement of Science, Washington (1978) at 100.

[23] The baby must be saved at all costs; anything less is illegal and immoral. That's what they say at Pediatric Hospital [a pseudonymous tertiary care center] anyway.

I'm afraid for Andrew, afraid for us. Afraid and ashamed. Why did we ever sign him into such a place. I don't understand why we had rights at Community and suddenly, we discover, we have no rights at Pediatric. Or why something is morally right at Community and morally wrong when you move some distance away. Legal here and illegal in the city.

Robert and Peggy Stinson, The Long Dying of Baby Andrew, Little, Brown, Boston (1983) at 46-47.

See also, O'Connor v. Donaldson, 422 U.S. 563 (1975); Note,

Obviously, just being in an institution affects a person's decisionmaking ability. Typically, patients forfeit control over what to wear, when to eat, and when to take medicines, for example. Furthermore, they almost inevitably lose substantial privacy—intimate body parts are examined, highly personal facts are written down, and someone they have never seen before may occupy the next bed. Finally, trust must be placed in strangers selected by the institution: care is given by professional experts who might well be, and who frequently are, substituted freely for one another to accommodate work schedules and educational needs. All these factors serve to isolate patients, rob them of their individuality, foster dependence, and diminish self-respect and self-confidence, even when illness, medication, and surgery have not already had these effects.[24] The situation can seriously impair patients' power to exercise self-determination and, thus, to be active participants in decisionmaking.[25]

Institutions also have customs and procedures that govern lines of authority and that are intended to guarantee the efficient, fair, and effective operation of the organization.[26] These are often largely implicit and informal, and their obscurity and complexity can keep a patient from knowing what policies are in effect and how he or she might affect personally relevant institutional practices.

The first hidden influence on patient choice is that, along with trying to serve individual patient's needs, administrators of health care institutions have other goals. Account books must be balanced; salaries paid; heat, light, and food provided; legal liability limited; research and education carried out; public health needs met; public image maintained; and the future of the institution assured.[27] The effects of national and local regulations, laws, and financial incentives and disincen-

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Developments in the Law of Civil Commitment of the Mentally Ill, 87 HARV. L. R. 1190 (1970).

[24] Erving Goffman, ASYLUMS, Anchor Books, Garden City, New York (1961) at 18-21; Talcott Parsons, THE SOCIAL SYSTEM, The Free Press, New York (1951) at 445-46.

[25] Of course, for some patients, who were debilitated before treatment, the net effect of an institution may be to *increase* the ability to make decisions on their own behalf.

[26] Harvey L. Smith, *Two Lines of Authority: The Hospital's Dilemma*, in E. Gartly Jaco, ed., PATIENTS, PHYSICIANS AND ILLNESS, The Free Press, New York (1958) at 468-77.

[27] Reinhold Niebuhr contends that, although individuals may on occasion be capable of a limited degree of altruism, groups or institutions invariably operate exclusively in their own self-interest: "The selfishness of human communities must be regarded as an inevitability." Reinhold Niebuhr, MORAL MAN AND IMMORAL SOCIETY, Charles Scribner's Sons, New York (1960) at 272 (originally published in 1932). *See also* John D. Thompson, *The Hospital—Its Role and*

tives are important in shaping the behavior of health care institutions. In recent years, for example, the rapid increase in health care expenditures has led to increased pressure to hold institutions accountable for the wise use of resources; reimbursement methods are being changed in ways that are intended to cause both profitmaking and nonprofit institutions to alter decisions about patient care.

Second, the character of most health care institutions, shaped by professional norms and societal values, strongly favors extending life whenever possible, regardless of resource use or personal suffering. Thus, the institutional arrangements made by administrators are frequently far from neutral in terms of the choices they leave for individual patients. A patient who chooses to forego aggressive therapy may have trouble finding emotional or material support, in addition to any more formal barriers to such decisions that are erected by the institution. For example, turning down aggressive care may leave no justification for an acute-care-hospital level of reimbursement, prompting the hospital to press for discharge or to inform the patient pointedly as to his or her liability for charges. Also, such a refusal may occasion formal adjudication of competence or of the relative weight of state interests.[28]

The Extent of Institutional Responsibility for Decisionmaking. Health care decisionmaking—whether in the context of life-sustaining treatment or otherwise—has traditionally been regarded by physicians as their province. In recent years, the law, medical ethics, and patients themselves have urged a more truly collaborative involvement of patients in the process. However, despite the marked growth in the importance of institutions as the setting of care and of "teams" of professional employees as providers of care, remarkably little consideration has been given to the proper role of hospitals and other institutions in health care decisionmaking. Traditionally, since only physicians—not hospitals—can practice medicine, it has been physicians who have had legal responsibility for the decisionmaking process—that is, for ensuring that patients are adequately informed about treatment options, have the capacity to make the treatment decision at hand, and actually do voluntarily consent. The few attempts by patients to impose liability on hospitals as well as, or instead of, physicians, on

Limitations in the Health Care System, in Lawrence Corey, Michael F. Epstein, and Steven E. Saltman, eds., MEDICINE IN A CHANGING SOCIETY, C.V. Mosby Co., St. Louis, Mo. (2d ed. 1977) at 107.

[28] *See* pp. 122-26 *infra* and pp. 31-32 *supra*. *See also* Willard Gaylin, *Still, A Person Owns Himself*, N.Y. TIMES, Dec. 12, 1982, at A-31.

the ground that they were not adequately informed about treatment before consenting to it, have uniformly failed.[29]

Nonetheless, hospitals have long been responsible for the acts and omissions of their employees.[30] If a staff nurse failed to give a medication prescribed by the patient's doctor, for example, the hospital might be liable for harms caused thereby. Similarly, a hospital is liable for the wrongful acts of an employee-physician, including failure to obtain a patient's informed consent to treatment,[31] though it is not liable for the professional defaults of those physicians who practice at the hospital as independent contractors.[32] By virtue of membership on a hospital's medical staff, a physician enjoys the "privilege" of admitting patients to the hospital and using its facilities and employees (such as nurses, technicians, and house staff) to assist in treating patients. Privileges to admit patients are not granted by the hospital as a corporate entity, but by the medical staff of the hospital, which is an independent legal entity composed of and operated by the physician members of the medical staff.

In recent years, the allocation of legal responsibility between the hospital on the one hand and individual physicians and the medical staff on the other has been subject to gradual but continuing redefinition by courts.[33] The unsettled nature of the law regarding an institution's reponsibilities concerning patients' decisionmaking provided the backdrop for the Commission's consideration of what the extent of those responsibilities ought to be.

Hospitals are increasingly (though still infrequently) held responsible for defaults committed by physicians treating

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[29] *See, e.g.*, Cooper v. Curry. 92 N.M. 417, 589 P.2d 201 (Ct. App. 1978); German v. Nichopolous, 577 S.W.2d 197 (Tenn. App. 1978); Parr v. Palmyra Park Hosp., 228 S.E.2d 596 (Ga. App. 1976).

[30] Many hospitals were formerly protected from suit by the doctrines of charitable or sovereign immunity. *See* Angela R. Holder, MEDICAL MALPRACTICE LAW, John Wiley & Sons, New York (1975) at 326-29. *See also* Richard T. DeGeorge, *The Moral Responsibility of the Hospital*, 7 J. MED. & PHIL. 87 (Feb. 1982).

[31] Cooper v. Curry, 92 N.M. 417, 589 P.2d 201, 203 (Ct. App. 1978) (by implication).

[32] *Id.*, citing Schloendorff v. Society of New York Hosp., 211 N.Y. 125, 105 N.E. 92 (1914).

[33] The landmark case in this process is Darling v. Charleston Community Memorial Hosp., 50 Ill. App.2d 253, 200 N.E.2d 149 (1964), *aff'd* 33 Ill.2d 326, 211 N.E.2d 253 (1965). *See generally* Neil L. Chayet and Thomas M. Reardon, *Trouble in the Medical Staff: A Practical Guide to Hospital Initiated Quality Assurance*, 7 AM. J. L. & MED. 301 (1981); Edward E. Hollowell, *Does Hospital Corporate Liability Extend to Medical Staff Supervision*?, 10 L., MED. & HEALTH CARE 225 (1982); Jay Alexander Gold, *Wiser than the Laws?: The Legal Accountability of the Medical Profession*, 7 AM. J. L. & MED. 145 (1981).

patients under their auspices and on their premises in situations in which the hospital's responsible officers (trustees or administrators) knew or reasonably should have known that the physician was not adhering to proper standards of medical practice. In parallel, hospitals are also gradually and increasingly being held legally liable for harmful results that befall patients at the hands of physicians whose lack of skills were not discovered because the medical staff did not adequately investigate into the physician's credentials when staff privileges were applied for and granted.[34]

Few cases have sought to impose liability on a hospital for a physician's failure to make an adequate disclosure of information to a patient, and none has been successful.[35] Nonetheless, as standards for making health care decisions—including decisions to forego life-sustaining treatment—evolve and become an accepted part of medical practice, hospitals are more likely to be held responsible when physicians to whom privileges have been accorded fail to abide by these decision-making procedures, at least in cases in which the hospital authorities knew or should have known of the physician's failure. Some state statutes or regulations now require hospitals to obtain adequate documentation of informed consent.[36] Even in the absence of statutory mandates, health care institutions have assumed some responsibility for the decision-making process, individually or through the accreditation process.[37] For example, the Joint Commission on the Accredita-

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[34] *See, e.g.*, Hollowell, *supra* note 33.

[35] Holding the hospital liable for such negligence has once been expressly rejected. The rationale for rejection—that it "would...interfere in the delicate doctor-patient relationship [by]...discourag[ing] hospitals from allowing physicians to use their facilities for novel or experimental medical procedures and [by]...inducing hospitals to discourage patients from undergoing such operations," Cooper v. Curry, 92 N.M. 417, 589 P.2d 201, 204 (Ct. App. 1978)—is not only factually tenuous but illogical and inconsistent with a proper understanding of requirements for informed consent. Hospitals need not discourage "novel or experimental medical procedures" if they were responsible for assuring patients' informed consent to such procedures, since informed consent is already required for nonexperimental as well as experimental procedures. *See, e.g.*, Demers v. Gerety, 85 N.M. 641, 515 P.2d 645 (Ct. App. 1973). Further, if adequate disclosure had the consequence of discouraging patients from undergoing experimental (or other) procedures, then it would have fulfilled its purpose of promoting patient self-determination.

[36] *See, e.g.*, Pennsylvania Department of Health, General and Special Hospitals, Patient's Bill of Rights, 10 Pa. Bull. 3761, 3676 § 103.22(8). (9) (Sept. 20, 1980); Minn. Stat. § 144.651(2).

[37] The voluntary assumption of a duty to which one would not otherwise be held often imposes a legal responsibility to comply with that duty. Thus, although hospitals arguably need not provide consent forms, use nurses to have them signed, or make inquiry of patients

tion of Hospitals (JCAH) requires that hospitals have a policy that stipulates when informed consent must be obtained.[38] Most health care institutions provide consent forms for the documentation of informed consent and permit or require employees, usually nurses, to have the patient sign the form; nurses are often cautioned not to allow patients to sign consent forms if they say their physicians have not explained the procedure or if it appears that the patients do not understand the treatment for which consent is sought.[39]

Thus, there is a growing recognition that health care institutions have a legitimate role in ensuring that patients are informed, voluntary decisionmakers, at least to the extent that this goal can be achieved through appropriate institutional supervision of the decisionmaking process. Although hospitals were once seen simply as facilities at which physicians could provide medical care, the responsibility of administrators for many decisions that impinge directly upon patient care is now recognized.[40] The particular dimensions of these responsibilities regarding life-sustaining treatment are still being developed.

Characteristics of Institutions. The nature of the major institutions where patients face decisions about life-sustaining treatment varies considerably. For example, acute care hospitals have a dominant predisposition to prolonging life; nursing homes have a weaker and more variable commitment to prolonging life; and hospices are characterized by an acceptance of death.

Acute care hospitals. There are over 7000 acute care hospitals in the United States with a total of 1.3 million beds.[41] Each year about one in every eight Americans spends some

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about whether the procedure has been explained and whether they understand it, their agreement to do so imposes a duty on them to do so and to do so in a responsible manner.

[38] Joint Commission on Accreditation of Hospitals, ACCREDITATION MANUAL FOR HOSPITALS, Chicago (1981) at 84-86.

[39] *See* Charles Lidz and Alan Meisel, *Informed Consent and the Structure of Medical Care* (1982), in President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, MAKING HEALTH CARE DECISIONS, VOLUME TWO: APPENDICES (EMPIRICAL STUDIES OF INFORMED CONSENT), U.S. Government Printing Office, Washington (1982) at 317; Demers v. Gerety, 85 N.M. 641, 515 P.2d 645, 648 (Ct. App. 1973).

[40] *See, e.g.*, Barry S. Bader and Andrew Burness, *Ethics: Boards Address Issues Beyond Allocation of Resources*, 35 TRUSTEE 14 (Oct. 1982).

[41] Michael Enright and Steven Jonas, *Hospitals*, in Steven Jonas, ed., HEALTH CARE DELIVERY IN THE UNITED STATES, Springer Publishing Co., New York (1981) at 169.

time as a hospital patient; it is estimated that 60-70% of the two million Americans who died in 1981 did so in a hospital.[42] In hospitals, a strong commitment to preserving life is combined with readily available means to try to do so. For a patient to decline procedures needed to make a definitive diagnosis, to reject vigorous treatment that might possibly bring longer life, or to find meaning in death and suffering is not only seen by most hospital personnel as aberrant or even suspect behavior, but may actually be very disruptive of the usual institutional routines and assumptions.[43]

The depersonalization and dependency that accompany living for a time in a large institution is particularly pronounced in hospitals. Many routine procedures—for example, denying patients an opportunity to review their charts or not telling them the nature and purpose of diagnostic tests[44]—undermine patient self-determination. Even hospital architecture and personnel patterns may aggravate confusion and depression.[45]

A great deal could be done to ameliorate the detrimental effects and to enhance the potentially beneficial effects of

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[42] See note 21 *supra*.

[43] One response to such disruptive behavior can be seen in the play, WHOSE LIFE IS IT ANYWAY?, the story of a paralyzed sculptor and his struggle to gain control over the decisions regarding his care. When his doctor prescribes valium over his objections because he "seems a little agitated," he reacts bitterly to the nurse who brings it:

> Because in an hour's time, you'll be bringing round a little white pill that is designed to insert rose-colored filters behind my eyes. It will calm me and soothe me and make me forget for a while that you have a lovely body.

Brian Clark, WHOSE LIFE IS IT ANYWAY?, Avon Books, New York (1978) at 17. *See also* Victor and Rosemary Zorza, A WAY TO DIE, Alfred A. Knopf, New York (1980) at 95; Robert M. Veatch, DEATH, DYING, AND THE BIOLOGICAL REVOLUTION, Yale Univ. Press, New Haven, Conn. (1976) at 279-87; Elisabeth Kübler-Ross, ON DEATH AND DYING, Macmillan Pub. Co., New York (1969) at 195-98.

[44] Budd N. Shenkin and David C. Warner, *Giving the Patient His Medical Record: A Proposal to Improve the System* (Sounding Board), 289 NEW ENG. J. MED. 688 (1973); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, MAKING HEALTH CARE DECISIONS, U.S. Government Printing Office, Washington (1982) at 80. *See also* "There are many ways in practice of not respecting a patient. For example, enclosing him in an exclusively technical world which is suitable only for the initiated, a world in which he cannot find any room for himself and his rights, and in which he is unable to influence the course of events." L.M. Cattoretti, *Moral Aspects*, in Robert G. Twycross and Vittorio Ventafridda, eds., THE CONTINUING CARE OF TERMINAL CANCER PATIENTS, Pergamon Press, New York (1980) at 7, 8.

[45] Gregg A. Warshaw *et al., Functional Disability in the Hospitalized Elderly*, 248 J.A.M.A. 847 (1982).

being treated for a life-threatening condition in a hospital. The most important change would be to make these problems more of a priority concern. Hospitals could minimize the institution's depersonalizing effects by, for example, encouraging patients to decorate their rooms or bring in personal items, protect their privacy, wear their own clothes, or even substantially direct their daily schedule. Some patients could go home for a few days to consider treatment options in a less intimidating setting. At the very least, hospital personnel could help patients understand how to function effectively within the institution's organization.

Whether hospitals can or should change their commitment to extending life is a more difficult issue. For the vast majority of patients, the institutions' strong commitment to saving lives is a source of trust and comfort. Even for patients who do not favor such treatment for themselves, encountering some degree of resistance to their wishes is a reminder that their lives are important to others. Nevertheless, patients should not face such marked and regular resistance to a decision to forego life-sustaining treatment as to either rob them of the right to self-determination or damage their mental or physical health, which might happen if others continually questioned the decision. Moreover, there are surely better ways to use institutions' scarce resources than to force them upon patients who truly prefer to forego them. The task facing hospitals and their personnel is to respond sensitively to the varied needs of individual patients in the context of a large, complex, and often overwhelming institution.

Nursing homes. Many people will spend some time in a long-term care (LTC) facility, typically a nursing home. The growing number of elderly in the population, the shifts in the composition and roles of families, and the initiation of Federal and state government funding led to a rapid expansion of long-term care facilities in the 1960s and 1970s.[46] Today nursing homes have over 1.4 million beds, and 64% of their residents remain there for more than a year.[47] Of the people residing in nursing homes, almost all are over 65 and 80% are over 75 years old.[48]

Admission to an LTC facility has substantial effects upon a person's prospects for a longer life. For a few patients, usually those subject to substantial abuse or neglect before admission, long-term care provides a chance for a longer and

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[46] *See e.g.*, Anne R. Somers, *Marital Status, Health, and the Use of Health; A Predicament for All*, WASH. POST, May 16, 1982, at A-1.

[47] National Center for Health Care Statistics, THE NATIONAL NURSING HOME SURVEY: 1977 SUMMARY FOR THE UNITED STATES, U.S. Dept. of Health and Human Services, Washington (1979) at 8, 29.

[48] Bruce C. Vladeck, UNLOVING CARE: THE NURSING HOME TRAGEDY, Basic Books, New York (1980) at 13.

better life. For many, however, admission involves leaving a familiar and supportive environment. A change in living arrangements is stressful for anyone; for the frail elderly, being "put into" a nursing home may actually increase the risk of dying in the year after admission.[49] Thus, deciding to enter a nursing home can really be a decision to forego the life-sustaining possibilities of remaining at home. Unfortunately, outpatient support services that would enable some people to continue to live independently are still not widely available, and many families are unable to bear the emotional and financial costs involved in caring for a severely dependent relative at home.[50]

The decision options available to residents in an LTC facility will be affected by a number of institutional and professional responses. Since many of these will never have been formally analyzed and adopted by an institution, there may be no way for a patient or surrogate to review them. Financial incentives and disincentives can make it difficult to obtain unscheduled physician visits, which are underpaid, and too easy to obtain a trip to the local emergency room, which is fairly well reimbursed. Some commentators feel that since rehospitalization usually "requalifies" the patient for (higher) Medicare benefits upon return to the nursing home, there is a substantial incentive for such long-term care facilities to send sick patients back to a hospital whether or not hospitalization offers the patients any benefit.[51]

Although all these incentives favor the use of technologically aggressive care, and although it is clear that some LTC institutions follow that course, others appear not to make aggressive care available to some patients. LTC facilities share hospitals' commitment to prolong life, but their bias in that direction is both less strong and less uniform. A study of

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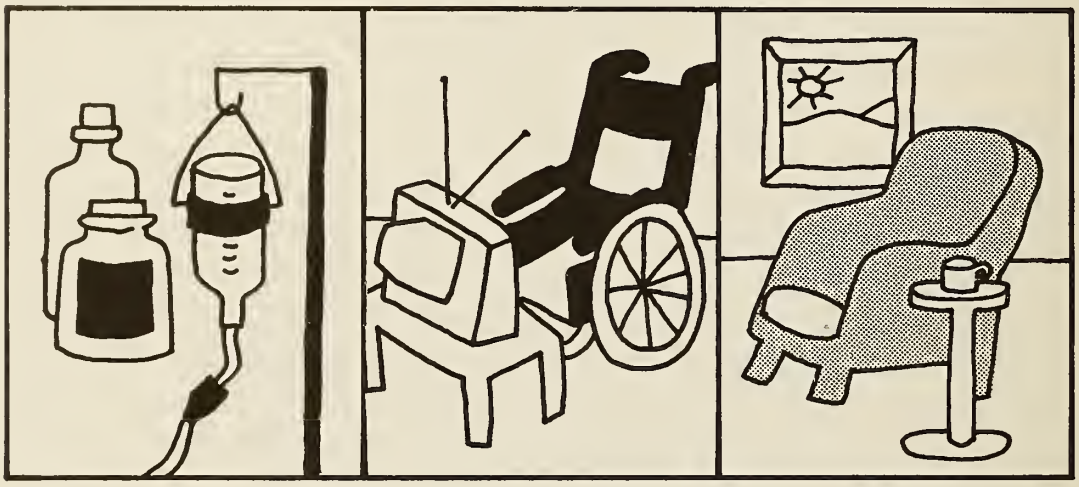
[49] *See, e.g.*, Richard T. Smith and Frederick W. Brand, *Effects of Enforced Relocation on Life Adjustment in a Nursing Home*, 6 INT'L J. AGING & HUM. DEV. 249 (1975); Stanislau V. Kasl, *Physical and Mental Health Effects of Involuntary Relocation and Institutionalization On the Elderly—A Review*, 62 AM. J. PUB. HEALTH 379 (1972).

[50] Elaine M. Brody, *Enviromental Factors in Dependency*, in A.N. Exton-Smith and J. Grimley Evans, eds., CARE OF THE ELDERLY: MEETING THE CHALLENGE OF DEPENDENCY, Grune and Stratton, New York (1977) at 81, 84; General Accounting Office, ENTERING A NURSING HOME—COSTLY IMPLICATIONS FOR MEDICAID AND THE ELDERLY, U.S. Government Printing Office, Washington (1979) at 9; Emmett Keeler and Robert L. Kane, *What is Special About Long-Term Care?*, in Robert L. Kane and Rosalie A. Kane, eds., VALUES AND LONG-TERM CARE, Lexington Books, Lexington, Mass. (1982) at 85, 94.

[51] ENTERING A NURSING HOME—COSTLY IMPLICATIONS FOR MEDICAID AND THE ELDERLY, *supra* note 50, at 26; James Lubitz and Ronald Deacon, *The Rise in the Incidence of Hospitalizations for the Aged, 1967 to 1979*, 3 HEALTH CARE FINANCING REV. 21, 37 (March 1982).

nontreatment of fever in LTC facilities showed that nearly half the patients with fever were not treated (with antibiotics or otherwise) and that the mortality in this group was—as expected—high (59%).[52] The untreated patients were more likely than others to have malignancies, to be bedridden, to be in pain, and to be residents of smaller facilities. Nontreatment in such settings seemed to be accepted, but the decisionmaking leading to it was rarely the object of scrutiny. (In fact, this is the only published study of nontreatment decisions in LTC facilities.) Although any treatment (or nontreatment) option may well be best for a particular patient, his or her chances of getting any specific choice seem largely to depend on the predilections of the institution's administrators, trustees, and employees, which are seldom made explicit.



The financial incentives established by reimbursement systems are another often unexamined influence on the decisionmaking of patients in LTC facilities. These institutions find it much more profitable, for example, to provide rehabilitation services and skilled care of wounds than psychiatric services and recreation.[53] It is not clear that the services provided are those that patients would choose, but it is clear that patients have little opportunity to alter the mix of services they receive or even to be informed of the importance of these administrative decisions. Thus, the responsibility of providing the most useful mix of services and informing patients and their surrogates of the opportunities that are not available must rest with those who establish the incentives (that is, the administrators of Medicaid programs) and those who respond

[52] Norman K. Brown and Donovan J. Thompson, *Nontreatment of Fever in Extended-Care Facilities*, 300 New Eng. J. Med. 1246 (1979).

[53] Such incentives probably contribute to Medicare spending about 6.6 times as much on enrollees who die in a calendar year than on those who live through the year. James Lubitz, Marian Gornick, and Ron Prihoda, *Use and Costs of Medicare Services in the Last Year of Life* (draft), Internal Working Paper, Health Care Financing Administration, Baltimore, Md. (Sept. 21, 1981). *See also* Human Resources Division, The Elderly Remain in Need of Mental Health Services, General Accounting Office, Gaithersburg, Md. (Sept. 16, 1982).

to them (predominantly nursing home administrators and trustees, though the patients' physicians and nurses may have a substantial role).

Very little has been done to encourage LTC institutions to develop good decisionmaking practices. Licensure of facilities and accreditation rests on a number of quality control measures but includes no consideration of decisionmaking factors such as the assessment of a patient's competence, the designation of surrogates, or the requirement to abide by a patient's decision.[54] Though residents often receive a "Bill of Rights" they are rarely taught to recognize infringements that occur. Advance directives about the care to be provided or foregone are often discouraged,[55] and serious assessment of the best interests of incompetent patients is often avoided.[56]

Like hospitals, LTC facilities can lessen the tendency of the institution to foster dependency and decisionmaking incapacity and can establish regular procedures for decisionmaking, including the assessment of residents' capacity to participate and the designation of surrogates. Since the practices and prevailing ethos of LTC facilities vary so greatly, they have an obligation to inform patients and families about these matters, both before and during the period of residence.[57] And since their patients are so commonly powerless to change practices, LTC institutions should be especially responsible in protecting the interests of the individual. Finally, improving decisionmaking in LTC facilities will require much further research on present practices and the likely effects of proposed improvements, a field that has received little scholarly attention.

Hospices. Whereas patients entering hospitals usually do so expecting to be cured and people entering nursing homes expect to stay for considerable periods of time and may not

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[54] Vladeck, *supra* note 48, at 155-57; *but see* American Health Care Association, *Questionably Competent Long Term Care Residents*, Washington (1982).

[55] *See* pp. 136-53 *infra*.

[56] Concerns that "many residents of long term care facilities exhibit some degree of inability to make, communicate or implement decisions" and a "growing awareness of the inadequacy of existing mechanisms for assuring the authority of decisions made by and on the behalf of questionably competent long term care residents" prompted the American Health Care Association to establish an ad hoc study committee, which published some analysis and tentative recommendations in *Questionably Competent Long Term Care Residents, supra* note 54, at 1, 2. *See also* Mary Devitt and Barry Checkoway, *Participation in Nursing Home Resident Councils: Promise and Practice*, 22 THE GERONTOLOGIST 49 (1982).

[57] Steven A. Levenson, Noel D. List, and Bo Zawwain, *Ethical Considerations in Critical and Terminal Illness in the Elderly*, 29 J. AM. GERIATRICS SOC. 563 (1981).

even be sick, people entering hospice programs not only know they are sick but also that their death will occur quite soon.[58] Before 1974 hospices were virtually unknown in the United States. Now this grass-roots movement has spawned an estimated 800 programs across the country.[59] Hospices were developed for the sole purpose of assisting dying patients—typically cancer patients who have exhausted all reasonable forms of curative treatment—to live their remaining weeks or months as free of symptoms and as much in control as possible.[60] They have been deliberately created as an alternative to traditional long-term care institutions.

Hospices are further distinguished from hospitals and nursing homes by several features. First, the term "hospice" refers not to a building, but to a concept of care.[61] Thus a hospice is a social and health care "institution," but not necessarily an inpatient facility. In the United States, most hospice care is delivered to people in their homes and many hospice programs provide only home care.[62] Second, the

[58] Nina Millett, *Hospice: Challenging Society's Approach to Death*, 4 Health & Soc. Work 131 (1979); Paul M. DuBois, The Hospice Way of Death, Human Sciences Press, New York (1980) at 48-59.

[59] In 1979 the General Accounting Office identified 59 operational hospices and another 73 in the planning stages. General Accounting Office, Hospice Care—A Growing Concept in the United States, U.S. Government Printing Office, Washington (1979) at 11. By 1980 the Joint Commission on Accreditation of Hospitals found 440 operational hospices (half of which had begun delivering services in that year) and almost 400 others getting ready to provide services. H. Peggy Falknor and Deborah Kugler, *JCAH Hospice Project Interim Report, Phase I*, Chicago, mimeo. (July 1981). Although no more recent surveys have been conducted, the National Hospice Organization estimates that there may now be as many as 800 hospice programs providing services.

[60] Although some hospice programs admit only cancer patients, most admit other patients as well. However, even then the vast majority of patients (estimated at 95% or more) have cancer. The virtual exclusion of other patients from hospices led to a study of the records of patients who died. Only 6 out of the 245 patients who would have been appropriate for hospice care had diseases other than cancer. Charles L. Breindel and Timothy O'Hare, *Analyzing the Hospice Market*, 60 Hosp. Progress 52 (Oct. 1979). Furthermore, hospices' focus on malignant disease may be due to recent advances in pain management, the anxiety people have about cancer, and the severe pain suffered by some cancer patients. Cicely Saunders, *Care for the Dying*, 3 Patient Care 2 (1976).

[61] Marian Osterweis and Daphne S. Champagne, *The U.S. Hospice Movement: Issues in Development*, 69 Am. J. Pub. Health 492 (1979).

[62] The Joint Commission on Accreditation of Hospitals surveyed 440 operational hospice programs in 1980 and found 46% to be hospital-based, most of which also provide care. Falknor and Kugler, *supra* note 59. The General Accounting Office reported that almost half the 59 operating hospices they surveyed in 1979 had no inpatient facilities.

patient and his or her family are considered to be the unit of care. Third, attention is given not only to physical needs, but also to emotional, social, and spiritual needs. Finally, hospice care is delivered by multidisciplinary teams of providers, including volunteers, on whom the hospice movement has depended heavily.[63]

Hospice programs vary substantially in their administrative arrangements and service offerings.[64] However, all hospices share a philosophy of care. Hospice development has been premised on the belief that home is almost always the best place to die[65] and that traditional medical care facilities, especially acute care hospitals, are inappropriate to the needs of the dying as well as unnecessarily costly.[66] They support families not only in their care of the patient but emotionally throughout a period of bereavement.

Like all other institutions, hospices have their particular ethos and operate under some constraints that necessarily impinge on the range of options available to patients and the ease of obtaining them. To their credit, hospices have been more self-conscious and self-critical than traditional institutions about these effects on patients. Because they recognize that their orientation differs from the norm in health care today, most hospices discuss their philosophy and approach with potential patients and their families in order to enhance

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Hospice Care—A Growing Concept in the United States, *supra* note 59. Fully 67% of hospices do not accept patients unless they have a primary care giver in the home at least 19 hours a day. Helen Butterfield-Picard and Josefina Magno, *Hospice the Adjective, Not the Noun*, 37 Am. Psychologist 1254, 1256 (1982).

[63] National Hospice Organization, *Standards of a Hospice Program of Care*, Washington, mimeo. (1981).

[64] Osterweis and Champagne, *supra* note 61; Hospice Care—A Growing Concept in the United States, *supra* note 59. While some programs initiated all their own services, others developed creative links with existing services. Some programs began as information and referral services, some rely at least partially on existing home care services, and others have become certified home health agencies in their own right. Although many hospices do not offer inpatient services, others may offer day care, short-term respite care, or long-term inpatient services. Inpatient care is provided in freestanding hospice facilities, in hospitals (either in special units or by roving hospice teams that care for the patient wherever he or she is), or occasionally in nursing homes.

[65] John M. Hinton, Dying, Penguin Books, Middlesex, Eng. (1967) at 148; Judy Alsofrom, *The 'Hospice' Way of Dying—At Home With Friends and Family*, Am. Med. News, Feb. 21, 1977, at 7-9.

[66] Cicely Saunders, *Hospice Care and Cancer*, mimeo. (1976) at 3; Claire F. Ryder and Diane M. Ross, *Terminal Care—Issues and Alternatives*, 92 Pub. Health Rep. 20 (1977); Alsofrom, *supra* note 65, at 7.

patient self-determination; many have rather explicit formal consent procedures.[67] Nonetheless, some patients do not realize that hospice admission amounts to a decision to forego many kinds of life-sustaining treatment (such as resuscitation, continuous cardiovascular monitoring, or chemotherapy).[68]

Hospices in this country, as in Great Britain, have deliberately tried to remain separate from traditional institutions.[69] When physically or administratively linked to them, hospices have taken steps to minimize the influence of the parent institutions. Hospice programs do have certain difficulties of their own. First, their institutional separateness can erect a hurdle to patients' reentering the traditional care setting should such a step become necessary or desirable.[70] Second, although

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[67] Patients and their families may be visited by a hospice worker prior to admission to a hospice program to discuss care needs as well as the program's philosophy and services. Although many hospices have no informed consent procedures or forms, others have rather explicit ones. For example, the consent form for the Washington Home Hospice in Washington, D.C., speaks of a "malignant tumor" for which "no further treatment is warranted," and the form for Hospice of Northern Virginia refers to care that is "palliative not curative" for disease with "life-limiting expectancy measured in weeks or months."

[68] Michael Van Scoy-Mosher, *An Oncologist's Case for No-Code Orders*, in A. Edward Doudera and J. Douglas Peters, eds., Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, AUPHA Press, Ann Arbor, Mich. (1982) at 16-17. That hospice programs provide symptom relief rather than cure is not always understood, even after signing consent forms that state this directly. Families of patients who died in the Washington Home Hospice were asked about the importance of several considerations in their decision to use the hospice. Almost 18% said the desire for cure was important. Marian Osterweis and Daphne S. Champagne, *The Washington Home Hospice: Case Study of an Inpatient Hospice*, report prepared for the Dreyfus Foundation, Washington (1982) at 19.

[69] In order to have home-like environments, open visiting, and individualized care, hospices have mostly been kept separate from other inpatient facilities. *See, e.g.*, Edward J. Spillane, *An Analysis of Catholic-Sponsored Hospices*, 60 Hosp. Progress 49 (March 1979); Sandol Stoddard, The Hospice Movement, Vintage Books, New York (1978) at 229-30. The first inpatient facilities tended to be freestanding, a trend encouraged by the National Cancer Institute, which undertook the construction costs of four hospices in the late 1970s; see note 72 *infra*.

[70] In its experimental programs to reimburse for hospice care, Blue Cross has required that the hospice physician have admitting privileges at a local hospital and that home care hospices have agreements with hospitals in order to guard against the possibility of isolating the patient from the traditional care system. Neil Hollander and David Ehrenfried, *Reimbursing Hospice Care: A Blue Cross and Blue Shield Perspective*, 60 Hosp. Progress 56, 76 (March 1979); Jack G. Coale, *The Hospice in the Health Care Continuum*, 5 Quality Rev. Bull. 23 (1979); Glen W. Davidson, *Five Models for Hospice Care, id.* at 9.

hospices pride themselves on providing an alternative to the norms embodied in acute care hospitals, their own norms and philosophy of care may make it emotionally (even if not practically) difficult to offer their patients some alternatives. For example, the enthusiasm and personal involvement of care givers—at hospices as at other institutions—can make patients feel guilty if they reject recommendations, resist plans of care, fail to respond to treatment (that is, report symptom relief), or fail to conform to institutional norms (which is a general acceptance of death). In contrast to hospitals that sometimes pressure patients to continue aggressive therapy after it has ceased to be warranted, hospices risk pressuring patients to accept death too readily and to forego potentially life-sustaining therapies too quickly.[71]

Until recently hospices have not had a firm financial base, relying instead on volunteers (both lay and professional), charitable donations, occasional demonstration grants from Federal agencies, and (rarely) reimbursement by third-party payors on an experimental basis.[72] Federal legislation passed in September 1982 will enable hospice services to be reimbursed under Medicare.[73] With this precedent, other third-party payors are expected to follow suit. Unfortunately, the legislation's requirements and incentives are likely to promote substantial and unjustified inequities in access to hospice care.[74] For example, the requirement that, in order to quality for this coverage, patients must be expected to die within six months, favors hospice care (which is of higher quality than

[71] Although this is a risk, there are no data to substantiate that this actually occurs. Peter Mudd, *High Ideals and Hard Cases: The Evolution of a Hospice*, 12 HASTINGS CTR. REP. 11 (April 1982); David J. Smith and Judith A. Granbois, *The American Way of Hospice, id.* at 8.

[72] The National Cancer Institute supported the construction, program development, and evaluation of four hospices beginning in 1974. Twenty-six additional hospices are currently being supported by the Health Care Financing Administration in conjunction with the Robert Wood Johnson and John A. Hartford Foundations in the largest demonstration program to date. Private insurers, especially the Blue Cross and Blue Shield Association, have also been experimenting with hospice reimbursement. *Hospice: Medicare's Newest Provider*, PERSPECTIVE/WASH. REP. ON MED. & HEALTH, Nov. 29, 1982.

[73] Sec. 122 of the Tax Equity and Fiscal Responsibility Act of 1982, Pub. Law No. 97-248, codified as 42 U.S.C.A. §§ 1395c to 1395f (West 1982).

[74] The legislation restricts inpatient hospice care that "may be provided only on an intermittent, nonroutine, and occasional basis and may not be provided consecutively over longer than five days," Pub. Law No. 97-248, § (dd)(1)(G), and further requires "assurances satisfactory to the Secretary that the aggregate number of days of inpatient care... provided in any 12-month period...does not exceed 20 percent" of the total number of hospice days, Pub. Law No. 97-248, § (dd)(2)(A)(iii).

that available to other elderly patients under Medicare). Also, this reimbursement policy will favor cancer patients, since they include the largest group of patients for whom prognostication of death within a few months can be made with acceptable reliability. And the severe limits on inpatient care favor patients who will not need such care because they have substantial and supportive families and homes. Yet there are certainly other patients with comparable medical burdens or with no families who on grounds of equity have a stronger claim to public support.[75]

The present legislation also provides considerable financial incentive for hospices to admit many people into their programs, but for short periods of time, which might mean admission is delayed until it is too late for the person to receive the substantial benefits of the program. Existing barriers to patients reentering traditional care are compounded under the new legislation, since a patient may only go back and forth between hospice and traditional care twice, and each movement results in loss of the benefits remaining in that period. These real and potential limits on patient choice could seriously undermine self-determination.

Several other concerns have been raised as a result of the recent legislation. If hospice programs become readily available, especially as a desirable place to send "failed" patients, hospital physicians and social workers may alter the care of patients in order to qualify them for hospice admission.[76] Commentators also fear that hospices will become big business, as the nursing home industry did when its financial base became secure, and lose their special value for dying patients.[77] In addition, if hospices are more generally available, efforts in traditional institutions to improve care of the dying might be slowed or abandoned altogether. "Experts in dying" may be

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[75] The history of hospices in England is of care directed toward middle class and the working poor. Hospices were seen as rescuing decent people from dying in workhouses. To have accepted parish relief (welfare) virtually disqualified an applicant for admission in the hospices established late in the nineteenth century. Carol Levine, *St. Luke's House: A Turn-of-the Century Hospice*, 12 HASTINGS CTR. REP. 12 (April 1982); Maureen A. Lally, *The Development of Terminal Care Facilities in England before the National Health Service*, Ph.D. Thesis, London School of Economics and Political Science, London (forthcoming).

[76] For example, they may undertake studies just to certify prognosis or to establish a tissue diagnosis. The issues discussed in the remainder of this section were addressed by several people at the National Hospice Organization Annual Meeting, Washington, Nov. 7-10, 1982. *See, e.g.*, Allen Buchanan, Marian Osterweis, and Joanne Lynn, *Ethical Problems in Hospice*, Nov. 10, 1982.

[77] Smith and Granbois, *supra* note 71, at 9.

created, just as experts in caring for the elderly have been, and care could be further fragmented.[78] Moreover, if hospice care is found to be less expensive than traditional care for at least some discernable categories of patients,[79] pressure may build for certain groups of patients to be limited to hospices or to have reimbursement provided at a rate no greater than for hospice care, thereby effectively denying those patients the alternative of more aggressive treatment.

The present virtues of hospices may depend upon the special commitment of dedicated care givers who have pioneered in this field. Mechanisms for careful and sensitive review should be part of present planning efforts if the benefits now offered by hospices are to be maintained when these facilities become a larger feature of patient care. The needed review will be unusual in that it must aim to monitor quality of care in such important but unfamiliar terms as whether the patient's role in decisionmaking is being fostered and whether death is, as far as possible, appropriate to the particular person's situation.

Summary of Changes Needed. Some constraints that institutional settings place on patient choice cannot be eliminated and some probably should not be. In the Commission's view, however, the failure to inform patients about limits on the services offered and other biases of an institution is unacceptable because it undermines patient self-determination. The process of decisionmaking should be responsive to individual differences and respectful of all persons, even the severely ill or dependent. The decision about whether to provide aggressive care for a seriously ill, wheelchair-bound, and forgetful person should not depend principally upon the character of the institution where the individual happens to be a patient, especially when this criterion is not the result of patients' and families' choices based on their knowledge of the institution's overall biases and procedures. Rather, the decision should be governed by the principles and practices of good decisionmaking.

The impact of various institutional constraints on patient choice could be diminished by ensuring both that patients are aware of the policies and ethos of the institutions they choose and that health care institutions are more responsive to individual patient needs, particularly through improving decisionmaking practices within the institution. Policymakers in the private as well as the public sector who establish the

[78] Expertise also may distance family and friends, who may feel less capable of correctly caring for the patients. *See* Mudd, *supra* note 71.

[79] Although the populations are not matched, it is instructive that one survey showed average costs of the last four weeks for a hospice patient to be $1290 and for a traditional home/hospital patient to be $3557. Am. Med. News, Dec. 10, 1982, at 23.

financial and legal incentives and disincentives for institutions should be attentive to the effects of their choices on the actions of institutions in regard to patient decisionmaking.

Patient Groups Raising Special Concerns

II

During the Commission's hearings and deliberations on this Report, several groups of patients were identified whose situations are currently raising questions about the decision-making process. Part II applies the more general analysis of the preceding chapters to the situations of patients who are incapable of deciding about medical care for themselves—with special attention to those who have permanently lost consciousness and to newborn children with potentially fatal illnesses—and to decisionmaking about resuscitating hospitalized patients who have a cardiac arrest.

The decision about whether or not to undertake life-sustaining treatment is more difficult to make when a patient cannot assess the options and make the choice. Chapter Four explores how these treatment decisions should be made for such patients. The first section of the chapter examines the problem of decisional incapacity itself: what does decision-making capacity entail, and who is to determine its absence or presence? The next section looks at the process of making decisions for such patients. Who is to serve as a surrogate decisionmaker? How is the surrogate to be designated? What standards should the surrogate use to make a decision? The role of "advance directives" in helping surrogates and health care providers make decisions on behalf of incapacitated patients is then examined. The procedures for this decision-making, especially the roles of the courts, health care institutions, and intrainstitutional ethics committees, are considered in the final section.

The particularly tragic circumstances of patients who have permanently lost consciousness prompted vigorous public discussion at the time of the *Quinlan* case.[1] These patients are

[1] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922

not dead, yet they cannot experience any of the activities of the world around them. How should such a patient be treated? What role should the family play in decisionmaking about the person's health care? What role, if any, should the law have in this process? To find answers to these questions, as the Commission attempts in Chapter Five, the general principles of this Report must be applied to circumstances in which patients' interests in health care are very attenuated.

While the Commission was working on this Report, several cases involving nontreatment of seriously ill newborn babies received wide publicity.[2] Chapter Six develops an analysis of the issues involved and recommends procedural and substantive policies to guide the decisionmaking in a manner that is protective of the interests of this special group of very vulnerable patients.

In Chapter Seven, the Commission recommends prudent policy for decisionmakers, care giving institutions, and the legal system in responding to the issue of when, why, and how it is appropriate for a physician to order that no attempt be made to resuscitate a patient. In the past two decades, hospitals have developed special teams that intervene rapidly to try to restore heartbeat when a patient's heart stops. Some hospitals have begun developing policies on decisions not to automatically attempt resuscitation, but much professional and public uncertainty persists about how such a practice should develop and be regulated.

(1976) (a period of interrupted breathing caused Karen Quinlan to sustain brain damage that left her in a persistent vegetative state; her father successfully sought appointment as her guardian for purposes of authorizing removal of her respirator).

[2] *See, e.g.*, Jay Mathews, *Brian West's Short, Tragic Life is Ended*, WASH. POST, Dec. 23, 1982, at A-5; Sheila Taub, *Withholding Treatment from Defective Newborns*, 10 L., MED. & HEALTH CARE 4 (1982); *Probe of Infant's Care Stirs Dispute in Ohio*, AM. MED. NEWS, Aug. 13, 1982, at 3.

Patients Who Lack Decisionmaking Capacity

4

Determination of Incapacity

In general, a person's choices regarding care ought to override the assessments of others about what best serves that person. Certain people, however, are incapable of making choices that reflect and promote their personal goals and values. Some patients—on account of age, incapacity, or inexperience—have an insufficiently developed set of goals and values. Some lack sufficient capabilities for understanding, communication, and reasoning; among patients facing life-threatening decisions, these faculties are frequently compromised. The principles for determining incapacity[1] and for making decisions on behalf of incapacitated patients that were developed by the Commission in its report on informed consent[2] therefore have special relevance to decisions to forego life-sustaining therapy.

Elements of the Determination. Determining whether a patient lacks capacity to make a particular health care decision requires assessing the patient's capability to understand information relevant to the decision, to communicate with care givers about it, and to reason about relevant alternatives against a background of reasonably stable personal values and life goals.[3] The ultimate objective of such an assessment is to

[1] The term "incapacitated" is used in this Report to refer to patients who lack decisional capacity, rather than referring to general illness or disability. "Incapacity" as used here is roughly equivalent to the conventional legal usage of the term "incompetent."

[2] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, MAKING HEALTH CARE DECISIONS, U.S. Government Printing Office, Washington (1982) at 169-88.

[3] *Id.* at 56-68.

diminish two types of errors: mistakenly preventing persons who ought to be considered competent from directing the course of their own treatment, and failing to protect incapacitated persons from the harmful effects of their decisions. Health care professionals usually play a substantial role in making these assessments; their conclusions are often not reviewed by officials outside health care institutions.[4]

Each determination of decisional incapacity focuses on a patient's actual functioning in a particular decisionmaking situation rather than simply on an individual's age or diagnosis. This approach is particularly germane for fairly mature children[5] and for mildly retarded or demented persons. What is relevant is whether a person is in fact capable of making a

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[4] Determining the patient's incapacity, designating and informing a surrogate, and helping the surrogate to decide may require time that is not available in an emergency. In general, because of its grave nature and consequences, a decision to forego life-saving treatment should be made under conditions that permit consultation, reflection, and reasoned decision. In an emergency, ordinarily treatment ought to be given if no decision has previously been made to forego treatment. *See generally* Alan Meisel, *The "Exceptions" to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking*, 1979 Wis. L. Rev. 413, 436, 476.

[5] Lois A. Weithorn and Susan B. Campbell, *The Competency of Children and Adolescents to Make Informed Treatment Decisions*, 53 Child Dev. 1589 (1982). *See also* Thomas Grisso, Juveniles' Waiver of Rights—Legal and Psychological Competence, Plenum Press, New York (1981); Gary B. Melton, Gerald P. Koocher, and Michael J. Saks, eds., Children's Competence to Consent, Plenum Press, New York (1983). Law has traditionally viewed people under a specified age—long set at 21 years and more recently at 18—as incompetent to make decisions about any contractual matters, including their own health care; this reverses the usual presumption of competency accorded adults. Some exceptions have been created for "emancipated" or "mature" minors, in recognition that sometimes children have adequate capacity to make decisions and social policy ought to find such decisions sufficient. The ever-expanding scope of these exceptions calls into question the underlying presumption; it may be more reasonable to ask—of any person at any age—"is *this* person capable of making *this* decision?" *See* A. M. Capron, *The Competence of Children as Self-Deciders in Biomedical Interventions*, in Willard Gaylin and Ruth Macklin, eds., Who Speaks for the Child, Plenum Press, New York (1982) at 57.

The Commission endorses this general trend, recognizing that there is an age, below about 14 years old, at which the traditional presumption of incompetence remains sensible. The presumption, however, is merely a starting point for inquiry. *See* Making Health Care Decisions, *supra* note 2, at 170, n.6, and Sanford L. Leikin, *Minors' Assent or Dissent to Medical Treatment*, in *id.*, Volume Three: Appendices (Studies on the Foundations of Informed Consent), at 175.

particular decision despite his or her youth, retardation, or dementia. Even when ultimate decisional authority is not left with a patient, reasonable efforts often should be made to give the person relevant information about the situation and the available options and to solicit and accommodate his or her preferences.

The Commission recommends that determinations of incapacity be made only when people lack the ability to make decisions that promote their well-being in conformity with their own values and preferences.[6] Rarely—infants and unconscious patients are the main exceptions—is incapacity absolute. Even people with impaired capacity usually still possess some ability to comprehend, to communicate, and to form and express a preference. The fact that a patient makes a highly idiosyncratic decision or has a medical or mental condition[7] similar to others who have been unable to make decisions that advance their own well-being may alert health care professionals to the possibility of decisional incapacity, but does not conclusively resolve the matter. "Decisionmaking incapacity" is not a medical or a psychiatric diagnostic category; it rests on a judgment of the type that an informed layperson might make—that a patient lacks sufficient ability to understand a situation and to make a choice in light of that understanding.[8] Indeed, when judges are called upon to make legal determinations of patients' competence, they consider the situation not as medical experts but as laypeople examining the data provided by health care personnel[9] and by others who know

[6] MAKING HEALTH CARE DECISIONS, *supra* note 2, at 172-73.

[7] In fact, a diagnosis of a major psychiatric illness only rarely in itself decides the question of the patient's capacity to make a particular treatment decision. There is no necessary correspondence between mental illness and the presence or absence of decisional capacity either in fact or in law. *See* Rogers v. Okin, 634 F.2d 650, 657-59 (1st Cir. 1980).

[8] *See also* Mark Perl and Earl E. Shelp, *Psychiatric Consultation Making Moral Dilemmas in Medicine*, 307 NEW ENG. J. MED. 618 (1982).

[9] The "mental status examination" is perhaps the best example of how professional expertise can be enlisted in making assessments of incapacity. Such an evaluation is intended, among other things, to elicit the patient's orientation to person, place, time, and situation, the patient's mood and affect, and the content of thought and perception, with an eye to any delusions and hallucinations; to assess intellectual capacity, that is, the patient's ability to comprehend abstract ideas and to make a reasoned judgment based on that ability; to review past history for evidence of any psychiatric disturbance that might affect the patient's current judgment; and to test the patient's recent and remote memory and logical sequencing.

In testimony before the Commission, Dr. Paul Hardy, a neurologist, cited the Earle Spring case as an example of need for careful

the individual well, and possibly from personal observation of the patient.

Finally, in any assessment of capacity, due care should be paid to the reasons for a particular patient's impaired capacity—not because the reasons are the determinant of whether the patient's judgment is to be honored, but because identification of the causes of incapacity may assist in their remedy or removal.[10] The Commission urges that those responsible for assessing capacity not be content with providing an answer to the question of whether or not a particular patient is incapacitated. Rather they should, to the extent feasible, attempt to remove barriers to decisional capacity.

Procedural Policies. A decision that a patient is incapacitated can be of great importance, both in the Commission's ethical analysis and in the function of law. Courts have generally held that, whereas competent patients may forego any treatment, incompetent patients' wishes can be overridden in order to protect their lives and well-being.[11] Since the

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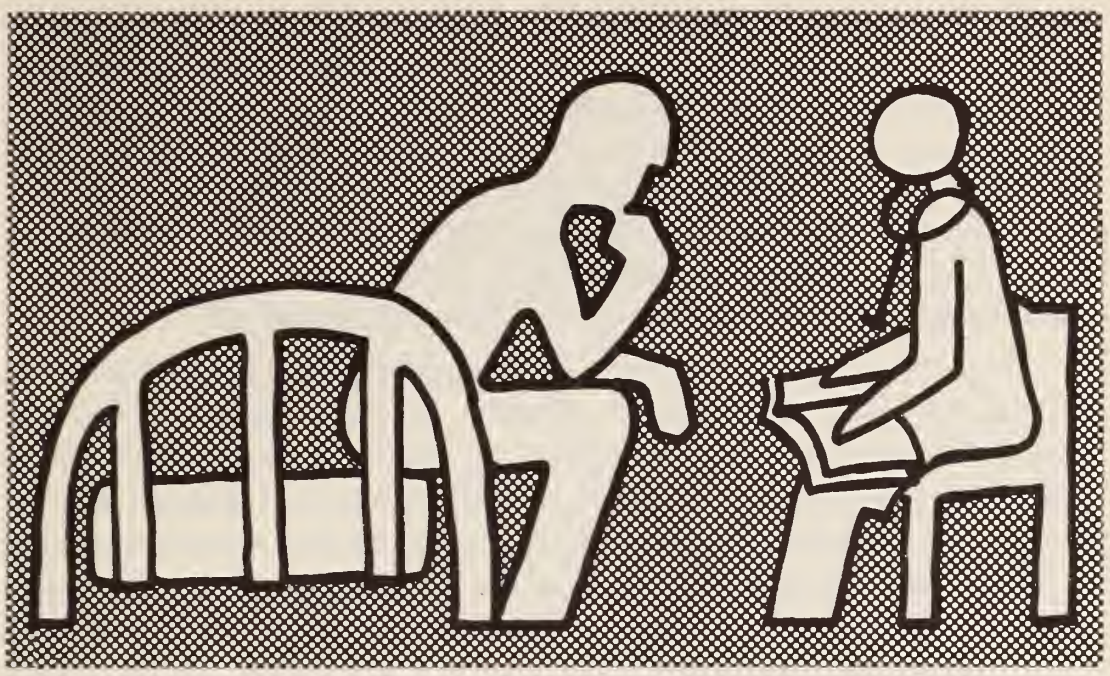
attention to underlying medical conditions bearing on determinations of competence. (Earle Spring's son petitioned a Massachusetts probate court for permission to stop dialysis treatments for his 79-year-old father who had been adjudged incompetent.)

> If there is a...major travesty about the Earle Spring case, it lies in the utter confusion on the part of the judicial community and the medical community on how to go about determining competency...There was some conflicting testimony as to whether he was indeed competent or not, and there was even confusion over the exact medical condition and diagnosis....[one psychiatrist] never once recognized that Mr. Spring was clearly aphasic and made certain determinations about Mr. Spring's competency based upon Mr. Spring's speech patterns....I think the field of neuropsychiatry and behavioral neurology will be able to help considerably in the months and years ahead to characterize and define whether an individual is competent or not.

Testimony of Paul Hardy, transcript of 10th meeting of the President's Commission (June 4, 1981) at 137-38; *In re* Spring, 405 N.E.2d 115 (Mass. 1980).

[10] *See* Paul S. Appelbaum and Loren H. Roth, *Clinical Issues in the Assessment of Competency*, 138 Am. J. Psychiatry 1462 (1981); Loren H. Roth *et al., The Dilemma of Denial in the Assessment of Competency to Refuse Treatment*, 139 Am. J. Psychiatry 910 (1982); Albert R. Jonsen, Mark Siegler, and William J. Winslade, Clinical Ethics, Macmillan Pub. Co., New York (1982) at 56-66.

[11] *Compare* Satz v. Perlmutter, 379 So.2d 359 (Fla. 1980); *In re* Quackenbush, 156 N.J. Super. 282, 383 A.2d 785 (1978); *In re* Osborne 294 A.2d 372 (D.C. App. 1972), Lane v. Candura, 376 N.E.2d 1232 (Mass. App. 1978); *with* John F. Kennedy Hosp. v. Heston, 279 A.2d 670 (N.J. 1971); and Application of President and Directors of Georgetown College, Inc., 331 F.2d 1000, *rehearing denied*, 331 F.2d 1010 (D.C. 1964). The court's authority to intervene arises largely from the



threshold issue of capacity is not only so weighty but often so complex,[12] it is of prime importance that assessments of incapacity be made carefully and adequately.

Health care professionals should therefore be familiar with the reason that a careful determination is important as well as with the procedures necessary to achieve it. Furthermore, health care institutions need to have clear policies as to who is responsible for assessing incapacity and by what standards. Institutions should ensure that those who assess capacity know the kinds of inquiries to make, the data to collect, and the records to keep. Finally, provisions also need to be made for reviewing determinations of incapacity both within the institution and, when necessary, through a judicial proceeding.

The first questions about a patient's decisionmaking capacity will usually be raised by attending health care personnel or by family members. Although formal legal procedures exist for adjudicating incompetency, a determination that a patient lacks the capacity to make some or all medical decisions independently is customarily made extra-judicially; only rarely is it reviewed in court. The legal status of such nonjudicial determinations is therefore uncertain, though this common practice is endorsed in the routine admonition to physicians to secure informed consent from the patient's next-of-kin,[13] in institutional regulations,[14] and even in court cases.[15]

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common-law doctrine of *parens patriae*, which recognizes that the state, through probate, juvenile, chancery, and other courts, must act as guardian for those people whose interests cannot otherwise be defended.

[12] *See, e.g.,* State Dept. of Human Services v. Northern, 563 S.W.2d 197 (Tenn. 1978); Lane v. Candura, 376 N.E.2d 1232 (Mass. App. 1978).

[13] *See, e.g., Consents*, 2 HOSPITAL LAW MANUAL, Aspen Systems, Rockville, Md. (1975) paragraph 4-12, at 58; Joseph H. King, Jr., THE

Some commentators, however, advocate requiring formal, judicial proceedings for all treatment decisions and especially for decisions to forego life-sustaining treatment on an incompetent patient.[16] Ideally, the courts are better equipped to protect the interests of incompetent patients; unfortunately, judicial proceedings, besides consuming time and resources, seem frequently to diffuse responsibility rather than increasing the acuity with which patients' interests are scrutinized.[17]

The Commission therefore believes that determinations of incapacity are best made without routine recourse to the courts. The Commission recommends that—except where state law clearly requires judicial intervention or where a real dispute persists after intrainstitutional review—determinations of decisional incapacity be made by the attending physician and regulated and reviewed at the institutional level, and that those who make and apply the law be encouraged to recognize the validity of such determinations. This recognition will require institutions to adopt procedures that merit such deference; in turn, it should reinforce for all participants in the decisionmaking process the importance of reaching a sound determination in each case.

Surrogate Decisionmaking

Identification of a Surrogate. When a patient lacks the capacity to make a decision, a surrogate decisionmaker should be designated. Ordinarily this will be the patient's next of kin,[18]

Law of Medical Malpractice in a Nutshell, West Publishing Co., St. Paul, Minn. (1977) at 140; Note, 14 Cin. L. Rev. 161, 170-72 (1940). The practice of obtaining consent from family members "is so well known in society at large that any individual who finds the prospect particularly odious has ample warning to make other arrangements better suited to protecting his own ends or interests." A. M. Capron, *Informed Consent in Catastrophic Disease Treatment and Research*, 123 U. Pa. L. Rev. 340, 424-25 (1974).

[14] Joint Commission on Accreditation of Hospitals, Accreditation Manual for Long Term Care Facilities, Chicago (1980) at 54.

[15] *See, e.g., In re* Dinnerstein 380 N.E.2d 134 (Mass. App. Ct. 1978); *In re* Nemser, 51 Misc.2d 616, 273 N.Y.S.2d 624 (Sup. Ct. 1966).

[16] John R. Robertson, The Rights of the Critically Ill, Bantam Books, New York (1983) at 33; Charles H. Baron, *Assuring "Detached but Passionate Investigation and Decison": The Role of Guardians Ad Litem in Saikewicz type Cases*, 4 Am. J. L. & Med. 111 (1978); *see also* Testimony of Jonathan Brant, transcript of 10th meeting of the President's Commission (June 4, 1981) at 27-35.

[17] Robert A. Burt, Taking Care of Strangers, The Free Press, New York (1979).

[18] In some cases when a guardian is needed, courts have gone to remarkable lengths to identify and appoint even distant family members. *See, e.g.*, Application of Long Island Jewish-Hillside Medical Center, 342 N.Y.S.2d 356 (Sup. Ct. 1973).

although it may be a close friend or another relative if the responsible health care professional judges that this other person is in fact the best advocate for the patient's interests.[19]

The Commission's broad use of the term "family" reflects a recognition of the fact that often those with most knowledge and concern for a patient are not relatives by blood or marriage.[20] Although more than one person may fall within this category, it will be necessary to designate one person as the principal decisionmaker for the incapacitated patient. One possibility is to define presumptive priority[21]—for example, that a person living with his or her spouse will speak for that spouse, that adult children will speak for elderly, widowed parents, etc. Although such presumptions may be helpful in some cases, the Commission believes that the health care practitioner is responsible for determining who should act as the patient's surrogate. No neat formulas will capture the complexities involved in determining who among a patient's friends and relatives knows the patient best and is most capable of making decisions in the patient's place. The responsibility is therefore on the practitioner either to assign this role of spokesperson (subject to appropriate institutional review) or to seek judicial appointment of a guardian.

The Commission believes that, for several reasons, a family member ought usually to be designated as surrogate to make health care decisions for an incapacitated patient in

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[19] On occasion courts have substituted friends as decisionmakers for incompetent patients, even over the protest of available family members. *See, e.g.*, George F. Will, *A Trip Toward Death*, NEWSWEEK 72 (Aug. 31, 1982) (an account of a California couple's attempt to gain custody, instead of the natural parents, of an institutionalized teenager with Down Syndrome), and the case involving Sharon Siebert, *see* note 29, Chapter Seven *infra*.

> [20] We have had situations where the only family member was a daughter on the West Coast who had not seen her father for the last 20 years.
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> He had lived with a drinking buddy of his for the last 20 years. Do we ignore this friend of his whose actions show that he cared also about him? Do we rely on the daughter who has no relationship in terms of interest in this patient? Often there are no family members at all, yet there may be friends and associates who knew the patient well. Do we ignore them because they do not constitute the traditional concept of family?
>
> Testimony of David Spackman, J.D., transcript of 10th meeting of the President's Commission (June 4, 1981) at 83.

[21] *See, e.g.*, Uniform Probate Code § 5-410.

consultation with the physician and other health care professionals[22]:

(1) The family is generally most concerned about the good of the patient.

(2) The family will also usually be most knowledgeable about the patient's goals, preferences, and values.

(3) The family deserves recognition as an important social unit that ought to be treated, within limits, as a responsible decisionmaker in matters that intimately affect its members.

(4) Especially in a society in which many other traditional forms of community have eroded, participation in a family is often an important dimension of personal fulfillment.

(5) Since a protected sphere of privacy and autonomy is required for the flourishing of this interpersonal union, institutions and the state should be reluctant to intrude, particularly regarding matters that are personal and on which there is a wide range of opinion in society.

The presumption that a family spokesperson is the appropriate surrogate may be challenged for any of a number of reasons: decisional incapacity of family members, unresolvable disagreement among competent adult members of the family about the correct decision, evidence of physical or psychological abuse or neglect of the patient by the family, an indication that the family's interests conflict substantially with the patient's, or evidence that the family intends to disregard the patient's stable values, preferences, or specific earlier instructions about treatment.[23] Even if all family members are disqualified from being the principal decisionmaker, for one or

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[22] *See* Richard A. McCormick and Robert M. Veatch, *The Preservation of Life and Self-Determination*, 41 THEOLOGICAL STUDIES 390 (June 1980).

[23] Although the majority of court cases brought on behalf of incompetent patients have involved closely related family members, one court noted the problems that might arise when defining the "family" for such purposes. In the combined appeal of *Storar* and *Eichner*, the majority criticized the "dissent which has abstractly endorsed the right of third parties, at least family members, to adopt a course of 'passive euthanasia' with respect to fatally ill incompetents....Presumably this right could only be exercised by family members, thus imposing a 'restriction' which itself is open-ended, reaching to the limits of the family tree." *In re* Storar, 420 N.E.2d 64, 67 n.2 (N.Y. 1981), *rev'g In re* Storar, 433 N.Y.S.2d 388 (App. Div. 1980) and *modifying* Eichner v. Dillon, 426 N.Y.S.2d 527 (App. Div. 1980). Usually families appearing before courts have been unanimous in their agreement that treatment should be foregone. *But see, In re* Nemser, 51 Misc.2d 616, 273 N.Y.S.2d 624 (Sup. Ct. 1966) (disagreement over amputation for 80-year-old mother, with physician son opposing

more of these reasons, it may still be appropriate to consult with the family in the decisionmaking process.

When an incapacitated patient has no family but does have a court-appointed guardian, special issues arise. Although the reasons for having an existing guardian act as the surrogate for medical decisions are weaker when the guardian is a stranger,[24] such a guardian should be the surrogate in the absence of disqualifying factors.[25] Since the guardian is likely to have been making a number of other decisions for the patient, he or she may have acquired a knowledge of the patient's beliefs, concerns, and values. In addition, the guardian has the sanction of court authority, which may ameliorate practitioners' concerns about civil liability. The decisions of court-appointed guardians about matters of importance to an incompetent person are usually subject to review and prior approval or disapproval by the court. Even when such oversight is not required, physicians should have greater leeway to seek to have the decisions of nonfamily guardians overridden than they do for the decisions of family surrogates, whose judgment should be accorded greater discretion.

If no family or legal guardian is initially available, a suitable surrogate decisionmaker should be designated to ensure a clear assignment of authority for decisionmaking and of responsibility for the exercise of this authority. Unless a suitable surrogate decisionmaker is identified, treatment decisions may lack continuity or may rest on an unclear foundation, making it difficult if not impossible to ensure that the process by which decisions are made is ethically and legally sound.

Although the concept of designating a surrogate for an individual who has no family is clearly sound, in practice there often are no appropriate individuals or agencies available to serve as surrogates. In the context of making decisions about life-sustaining treatment, this is likely to be an especially prevalent problem because of the large number of elderly patients with no family or friends available. One attorney, testifying before the Commission, commented that

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treatment and lawyer son in favor). *See also* Rhonda J.V. Montgomery, *Impact of Institutional Care Policies on Family Integration*, 22 THE GERONTOLOGIST 54 (1982).

[24] If the guardian had been nominated by the patient prior to his or her incapacitation, he or she would almost always be included in the definition of family used here.

[25] Allen E. Buchanan, *Medical Paternalism or Legal Imperialism: Not the Only Alternatives for Handling Saikewicz-type Cases*, 5 AM. J. L. & MED. 97, 111 (1979). If an incapacitated patient has both a competent family and a legal guardian, they should function together as principal decisionmakers to the extent permitted by local law, and family members should know that they can challenge the guardian in court.

> the undeniable tragic fact of the matter is that many, many people, into the thousands, do not have a brother or sister, a mother, a parent, a daughter, or son who can be appointed guardian. There isn't anybody. A lot of them are in institutions, and with the deinstitutionalization process, a lot are now in the community. And there isn't a person to appoint. And we have run out of volunteers.[26]

In some states, public guardianship agencies have been established, but they are underfunded and understaffed and quickly become overburdened with responsibility.[27] Proposals have also been made to establish private, nonprofit social service corporations to provide guardianship services, though they would ordinarily have to rely on public funding unless limited to patients with substantial estates.[28] Regardless of the source of payment, the estimated cost is very high.[29]

In addition, the logistics of having a guardian appointed are quite cumbersome. The head of a corporate guardianship endeavor described the legal process by which guardians have traditionally been appointed as "woefully medieval and oftentimes not worthy of the description of a legal hearing."[30] Another witness stated that in one large American city, it can often take up to eight months to have a guardian appointed, other than for emergency treatment.[31]

Whether or not the selection of a surrogate decisionmaker requires judicial proceedings is an issue that has not been faced squarely by many courts. The New Jersey Supreme Court upheld the appointment of Karen Quinlan's father as her guardian, thus confirming the notion that a close relative is an

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[26] Testimony of Paul Rogers, transcript of 10th meeting of the President's Commission (June 4, 1981) at 106.

[27] John J. Regan, *Protective Services for the Elderly: Commitment, Guardianship, and Alternatives*, 13 WM. & MARY L. REV. 569, 609-12 (1972); Rogers, *supra* note 26, at 107; Maureen Morrisey, *Guardians Ad Litem: An Educational Program in Virginia*, 22 THE GERONTOLOGIST 301 (1982).

[28] Testimony of Frank Repenseck, Director, Dade County Guardianship Program, transcript of 8th meeting of the President's Commission (April 9, 1981) at 187-204; Rogers, *supra* note 26, at 107.

[29] The estimated cost given to the Commission for a proposed "corporate" guardianship service in Massachusetts was $3100 per patient per year at 1981 prices. Rogers, *supra* note 26, at 109.

[30] *Id*, at 104. *See also* George J. Alexander, *Premature Probate: A Different Perspective on Guardianship for the Elderly*, 31 STAN. L. REV. 1003 (1979).

[31] Testimony of Dr. Marianne Prout, transcript of 10th meeting of the President's Commission (June 4, 1981) at 12. This witness testified that a temporary guardian can be appointed in an emergency within a few hours, though even that delay is often detrimental to patient care.

appropriate surrogate, but it did not explicitly pass on the issue of whether or not the surrogate must be court-designated.[32] By contrast, the Massachusetts Supreme Judicial Court, in a series of cases, has insisted that a court-appointed guardian generally be named as surrogate for a patient who lacks decisional capacity (subject to direct judicial oversight on appropriate matters), at least when the patient has no family members who are willing and available to participate in the decisionmaking process.[33]

Although all states have statutory provisions allowing the appointment of guardians, none of the statutes deal with whether a person who makes a decision to forego life-sustaining treatment on behalf of another must first obtain sanction from a court to act as decisionmaker. When family members are available and the patient is terminally ill, no court has required judicial appointment of a family member to act as surrogate, although the issue has not yet been presented in this way. In *Dinnerstein*,[34] the Appeals Court of Massachusetts held that the court need not review an order against resuscitation for a "hopeless" patient with loving family. Other judicial cases involving life-sustaining treatment have usually been brought to court on an application for the appointment of a guardian, or on an application of an individual to be appointed guardian for the express purpose of making a decision to forego treatment.[35] In other words, the question of whether a judicially appointed guardian is necessary in all such cases has been sidestepped, and courts have instead considered whether a particular individual is suited to be a guardian and/or whether treatment can be discontinued.

In the Commission's view, the cumbersomeness and costs of legal guardianship strongly militate against its use and ought to be taken into account by lawmakers before they require that decisions about life-sustaining treatment be made by judicially appointed guardians. Yet where the law or the patient's situation clearly requires a judicially appointed guardian, the Commission recommends that provision be made for the establishment of adequate guardianship services. In light of the gap in the law as to when and whether guardians are necessary, the Commission recommends that health care institutions should have policies for the designation of a

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[32] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

[33] *See* Custody of a Minor, 385 Mass. 697, 434 N.E.2d 601, 607-09 (1982); Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417 (Mass. 1977). *See also* pp. 153-57 *infra*.

[34] *In re* Dinnerstein, 380 N.E.2d 134 (Mass. App. Ct. 1978).

[35] *See, e.g., In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976); State Department of Human Services v. Northern, 563 S.W.2d 197 (Tenn. Ct. App. 1978).

surrogate and should be responsible both for providing surrogates for patients who have no close family and for appropriate referral of disputed cases to court.

Substantive Principles of Surrogate Decisionmaking. The procedures for decisionmaking on behalf of incapacitated patients—whether they are established by common practice, courts, or legislatures and whether they require formal adjudication or defer to physician judgment—do nothing more than designate the centers for responsibility and the processes to be followed. Knowing what issues to take into account or what weight to give potentially conflicting interests is still necessary for the surrogate who is trying to make morally justified decisions.

The two values that guide decisionmaking for competent patients—promoting patient welfare and respecting patient self-determination—should also guide decisionmaking for incapacitated patients, though their implementation must differ. These values are reflected, roughly speaking, in the two standards that have traditionally guided decisionmaking for the incapacitated: "substituted judgment" and "best interests." Although these standards are now used in health care situations, they have their origins in a different context—namely, the resolution of family disputes and decisions about the control of the property of legal incompetents. These doctrines were developed to instruct guardians about the boundaries of their powers and to provide a standard for guidance of courts that must review decisions proposed or made by a guardian.[36]

Despite the long legal history of both these standards, they provide only hazy guidance for decisionmaking even in their original contexts, not to mention in the often far more complex, urgent, and personal setting of health care. Although a number of recent cases involving decisions about health care for incapacitated patients have given courts the opportunity to clarify their meanings, increased confusion has actually resulted from some of these attempts to add precision to the doctrines.

Substituted judgment. The substituted judgment standard requires that a surrogate attempt to reach the decision that the incapacitated person would make if he or she were able to choose.[37] As a result, the patient's own definition of "well-being" is respected; indeed, the patient's interest in "self-

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[36] *See generally* A.M. Capron, *The Authority of Others to Decide about Biomedical Interventions with Incompetents*, in Gaylin and Macklin, *supra* note 5, at 115, 119-133; Lawrence A. Frolik, *Plenary Guardianship: An Analysis, a Critique, and a Proposal for Reform*, 23 ARIZ. L. REV. 599 (1981).

[37] For example, the substituted judgment doctrine permits a surrogate to make a gift of some of an incompetent's assets to a relative to whom the incompetent person had previously made gifts. The court

determination" is preserved to a certain extent, given the fundamental reality that the patient is incapable of making a valid contemporaneous choice.

A surrogate's decision is limited, however, by two general external constraints. First, the surrogate is circumscribed by the same limitations that society legitimately imposes on patients who are capable of deciding for themselves, such as not compromising public health (as in refusing a mandatory vaccination) or not taking steps contrary to the criminal law (for example, through intentional maiming). Second, there are certain decisions that a patient might be permitted to make because of the strong protection afforded self-determination but that are outside the discretion of a substitute decisionmaker. The line is drawn at actions whose potential adverse effects on well-being, as that concept is commonly understood, are so great that they can be permitted only when sufficiently directly chosen by a competent patient. For example, people may choose for themselves not to have a life-sustaining blood transfusion, but a similar decision by a surrogate would require more direct confirmation of the patient's goals and values than a generally expressed disinclination to receive transfusions. Thus even the substituted judgment standard—which is considered "subjective"—is constrained by limitations arising from the inescapable uncertainty of the evidence as to patients' competent preferences and from the significance and irreversibility of the particular medical decisions.

The substituted judgment standard can be used only if a patient was once capable of developing views relevant to the matter at hand; further, there must be reliable evidence of those views. From an ethical perspective—and probably from the perspective of evidentiary adequacy in court as well—the best proof is the patient's prior expression of views about the current medical situation, particularly when abstract statements have been substantiated by choices by the person in similar situations.[38] For example, a person who has repeatedly

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will approve such a gift to the extent that it does not endanger funds needed for the incompetent's support—even if the incompetent person would have been willing to be more generous.

[38] For example, the New Jersey Supreme Court refused to give weight to statements Karen Ann Quinlan was reported to have made about her "distaste for continuance of life by extraordinary medical procedures, under circumstances not unlike those of the present case." Despite the fact that "she was said to have firmly evinced her wish," the court would not consider them because "they were remote and impersonal, [and] lacked significant probative weight." *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 653, *cert. denied*, 429 U.S. 922 (1976). In contrast, the New York Court of Appeals accepted the prior competent statements, made in the context of a discussion of the moral implications of the *Quinlan* case and in associated classroom teaching, of a religious brother whose medical condition paralleled Quin-

been willing to undergo painful treatments in order to live long enough to see his or her children grow up is likely to want to do so again as long as that goal might be realized. While decisions may be based on a patient's general values, goals, and desires, courts are more likely to honor written statements (such as a "living will") than oral ones because they make it plainer that the person actually expressed the views in question and that the statements were specifically intended to direct what should be done for the individual in certain situations.

In some cases, although a patient lacks the capacity to make a contemporaneous decision about foregoing treatment and may even have been declared legally incompetent, he or she may still express a view about treatment, and surrogates should evaluate the relevance of such statements when making a substituted judgment.[39]

Best interests. Because many people have not given serious thought to how they would want to be treated under particular circumstances, or at least have failed to tell others their thoughts, surrogates often lack guidance for making a substituted judgment. Furthermore, some patients have never been competent; thus, their subjective wishes, real or hypothetical, are impossible to discern with any certainty.[40] In these situations, surrogate decisionmakers will be unable to make a valid substituted judgment; instead, they must try to make a choice for the patient that seeks to implement what is in that

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lan's. Brother Fox had said that "he would not want any of this 'extraordinary business' done for him under those circumstances." *In re* Storar, 52 N.Y.2d 363, 420 N.E.2d 64, 68 (1981).

[39] This endeavor is especially difficult when the person expresses inconsistent or contradictory views or holds views that fluctuate over time. *See* State Dept. of Human Services v. Northern, 563 S.W.2d 197 (Tenn. Ct. App. 1978), involving an elderly woman suffering from gangrene who refused to consent to the amputation of her gangrenous feet, a procedure her physicians believed necessary to save her life. Despite the fact that she was, as described by the court, "an intelligent, lucid, communicative and articulate individual," she did not "accept the fact of the serious condition of her feet and [was] unwilling to discuss the seriousness of such condition or its fatal potentiality." Furthermore, the woman "had no wish to die." *Id.* at 205. Thus, the inconsistency of her views was that she both wanted to continue to live and to retain her feet, a position that was most untenable in light of the medical evidence. The court determined that this evidenced incapacity regarding the treatment decision and ordered the amputation.

[40] Allen E. Buchanan, *The Limits of Proxy Decision Making for Incompetents*, 29 U.C.L.A. L. Rev. 393 (1981); John A. Robertson, *Legal Criteria for Orders Not to Resuscitate: A Response to Justice Liacos*, in A. Edward Doudera and J. Douglas Peters, eds., Legal and Ethical Aspects of Treating Critically and Terminally Ill Patients, AUPHA Press, Ann Arbor, Mich. (1982) at 159-63. *See also, In re* Storar, 52 N.Y.2d 363, 420 N.E.2d 64 (1981).

person's best interests by reference to more objective, societally shared criteria.[41] Thus the best interests standard does not rest on the value of self-determination but solely on protection of patients' welfare.[42]

In assessing whether a procedure or course of treatment would be in a patient's best interests, the surrogate must take into account such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained.[43] An accurate assessment will encompass consideration of the satisfaction of present desires, the opportunities for future satisfactions, and the possibility of developing or regaining the capacity for self-determination.

The impact of a decision on an incapacitated patient's loved ones may be taken into account in determining someone's best interests, for most people do have an important interest in the well-being of their families or close associates.[44]

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[41] The best interests doctrine has received most attention in law in cases involving questions of the custody and care of children, *see generally* 2 C.J.S., Adoption of Persons §§ 90-91 (1972), and in cases involving the expenditure of trust funds, *see generally* 76 Am. Jur. 2d, Trusts § 288 (1975), neither of which are likely to be accurate guides to understanding how the standard ought to operate in instances of surrogate health care decisionmaking for adults who lack decisionmaking capacity.

For a discussion of the best interests standard, *see* Joel Feinberg, Rights, Justice, and the Bounds of Liberty, Princeton Univ. Press, Princeton, N.J. (1980); Ruth Macklin, *Return to the Best Interests of the Child*, in Gaylin and Macklin, *supra* note 5, at 265; Capron, *supra* note 36; Joseph Goldstein, Anna Freud, and Albert J. Solnit, Beyond the Best Interests of the Child, The Free Press, New York (1979).

[42] This does not mean the surrogate must choose the means that an individual physician believes is most likely to benefit the patient maximally but only that the surrogate must have reason to believe that the patient will be maximally benefitted. When multiple therapies have different risks, collateral effects, and degrees of success, the surrogate should try to weigh these reasonably and the surrogate's decision should be honored as long as a significant proportion of physicians would agree, whether or not this particular physician does. However, the best interests standard would preclude the surrogate from choosing a therapy that is professionally unacceptable, even if the surrogate might choose that treatment for him or herself.

[43] The phrase "quality of life" has been used in differing ways; sometimes it refers to the value that the continuation of life has for the patient, and other times to the value that others find in the continuation of the patient's life, perhaps in terms of their estimates of the patient's actual or potential productivity or social contribution. In applying the best interest principle, the Commission is concerned with the value of the patient's life for the patient.

[44] In the context of a decision about the forcible administration of antipsychotic medication, the Massachusetts Supreme Court counted the

To avoid abuse, however, especially stringent standards of evidence should be required to support a claim that the average, reasonable person in the patient's position would disregard personal interests (for example, in prolonging life or avoiding suffering) in order to avoid creating emotional or financial burdens for their family or other people to whom they were close.[45]

The recommended standard. The Commission believes that, when possible, decisionmaking for incapacitated patients should be guided by the principle of substituted judgment, which promotes the underlying values of self-determination and well-being better than the best interests standard does. When a patient's likely decision is unknown, however, a surrogate decisionmaker should use the best interests standard and choose a course that will promote the patient's well-being as it would probably be conceived by a reasonable person in the patient's circumstances. On certain points, of course, no consensus may exist about what most people would prefer, and surrogates retain discretion to choose among a range of acceptable choices.

Advance Directives

An "advance directive" lets people anticipate that they may be unable to participate in future decisions about their own health care—an "instruction directive" specifies the types of care a person wants (or does not want) to receive; a "proxy directive" specifies the surrogate a person wants to make such decisions if the person is ever unable to do so[46]; and the two forms may be combined. Honoring such a directive shows respect for self-determination in that it fulfills two of the three values that underlie self-determination. First, following a directive, particularly one that gives specific instructions about

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"impact upon the ward's family" as one of six factors to be considered in reaching a substituted judgment:

> An individual who is part of a closely knit family would doubtless take into account the impact his acceptance or refusal of treatment would likely have on his family. Such a factor is likewise to be considered in determining the probable wishes of one who is incapable of formulating or expressing them himself. In any choice between proposed treatments which entail grossly different expenditures of time or money by the incompetent's family, it would be appropriate to consider whether a factor in the incompetent's decision would have been the desire to minimize the burden on his family.

In re Richard Roe III, 421 N.E.2d 40, 58 (Mass. 1981).

[45] Leach v. Akron General Medical Center, 426 N.E.2d 809 (Ohio Com. Pl. 1980).

[46] This Report uses "proxy" to mean a surrogate whose appointment rests on the designation of the patient while competent.

types of acceptable and unacceptable interventions, fulfills the instrumental role of self-determination by promoting the patient's subjective, individual evaluation of well-being. Second, honoring the directive shows respect for the patient as a person.

An advance directive does not, however, provide self-determination in the sense of active moral agency by the patient on his or her own behalf. The discussion between patient and health care professional leading up to a directive would involve active participation and shared decisionmaking, but at the point of actual decision the patient is incapable of participating. Consequently, although self-determination is involved when a patient establishes a way to project his or her wishes into a time of anticipated incapacity, it is a sense of self-determination lacking in one important attribute: active, contemporaneous personal choice. Hence a decision not to follow an advance directive may sometimes be justified even when it would not be acceptable to disregard a competent patient's contemporaneous choice. Such a decision would most often rest on a finding that the patient did not adequately envision and consider the particular situation within which the actual medical decision must be made.

Advance directives are not confined to decisions to forego life-sustaining treatment but may be drafted for use in any health care situation in which people anticipate they will lack capacity to make decisions for themselves. However, the best-known type of directive—formulated pursuant to a "natural death" act—does deal with decisions to forego life-sustaining treatment. Beginning with the passage in 1976 of the California Natural Death Act, 14 states and the District of Columbia have enacted statutory authorization for the formulation of advance directives to forego life-sustaining treatment (see Figure 1).[47] In addition, 42 states have enacted "durable power of attorney" statutes; though developed in the context of law concerning property, these statutes may be used to provide a legal authority for an advance directive (see Figure 1).[48]

Despite a number of unresolved issues about how advance directives should be drafted, given legal effect, and used in clinical practice, the Commission recommends that advance directives should expressly be endowed with legal effect under

[47] Appendix D, pp. 309-87 *infra*. One of these states, Virginia, has a statute awaiting the Governor's signature as of March 17, 1983. *See also* Michael Garland, *Politics, Legislation and Natural Death*, 6 HASTINGS CTR. REP. 5 (Oct. 1976); Richard A. McCormick and André Hellegers, *Legislation and the Living Will*, 136 AMERICA 210 (1977); Barry Keene, *The Natural Death Act: A Well-Baby Check-up on Its First Birthday*, 315 ANNALS N.Y. ACAD. SCI. 376 (1978).

[48] Appendix E, pp. 389-437 *infra*. In one additional state, Louisiana, all powers of attorney are durable unless otherwise specified.

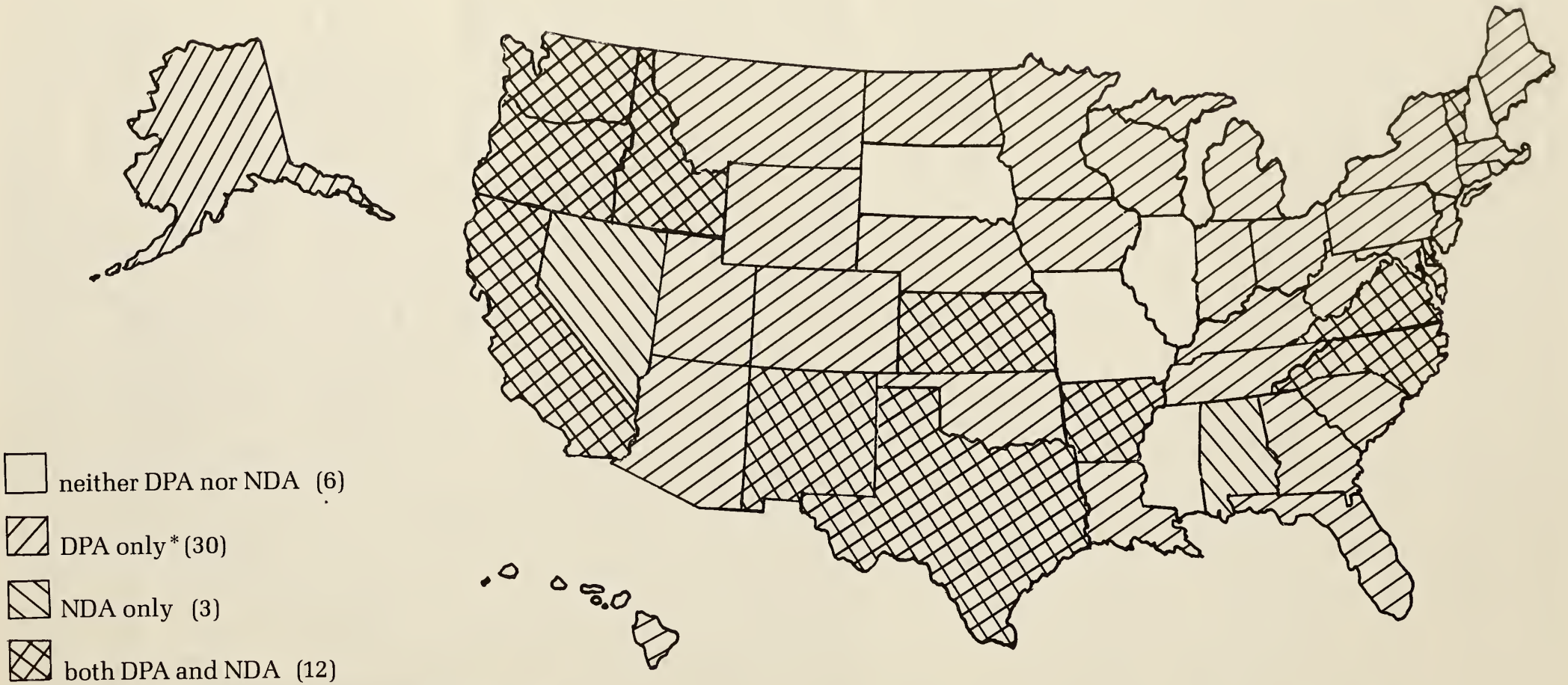

Figure 1: "Natural Death" Acts (NDA) and Durable Power of Attorney (DPA) Acts

state law. For such documents to assist decisionmaking, however, people must be encouraged to develop them for their individual use, and health care professionals should be encouraged to respect and abide by advance directives whenever reasonably possible, even without specific legislative authority.

Existing Alternative Documents. Several forms of advance directives are currently used. "Living wills" were initially developed as documents without any binding legal effects; they are ordinarily instruction directives. The intent behind the original "natural death" act was simply to give legal recognition to living wills drafted according to certain established requirements. They are primarily instruction directives, although their terms are poorly enough defined that the physician and surrogate who will carry them out will have to make substantial interpretations. "Durable power of attorney" statutes are primarily proxy directives, although by limiting or describing the circumstances in which they are to operate they also contain elements of instruction directives. Furthermore, durable powers of attorney may incorporate extensive personal instructions.

Living wills. People's concerns about the loss of ability to direct care at the end of their lives have lead a number of commentators as well as religious, educational, and professional groups to promulgate documents, usually refered to as living wills,[49] by which individuals can indicate their preference not to be given "heroic" or "extraordinary" treatments. There have been many versions proposed, varying widely in their specificity. Some explicitly detailed directives have been drafted by physicians—outlining a litany of treatments to be foregone or disabilities they would not wish to suffer in their final days.[50] The model living wills proposed by educational groups have somewhat more general language[51]; they typically mention "life-sustaining procedures which would serve only to artificially prolong the dying process." One New York group has distributed millions of living wills.[52] The columnist who

[49] *Questions and Answers About the Living Wills* (pamphlet), CONCERN FOR DYING, New York (n.d.).

[50] Walter Modell, *A "Will" to Live* (Sounding Board), 290 NEW ENG. J. MED. 907 (1974); *Last Rights* (Letters), 295 NEW ENG. J. MED. 1139 (1976); *See also* Sissela Bok, *Personal Directions for Care at the End of Life*, 295 NEW ENG. J. MED. 367 (1976).

[51] Among the groups that have promulgated living wills are the Society for the Right to Die, the Euthanasia Education Council, the American Protestant Hospital Association, the American Catholic Hospital Association, and the American Public Health Association.

[52] *See* note 49 *supra*.

writes "Dear Abby" reports receiving tens of thousands of requests for copies each time she deals with the subject.[53] Despite their popularity, their legal force and effect is uncertain.[54] The absence of explicit statutory authorization in most jurisdictions raises a number of important issues that patients and their lawyers or other advisors should keep in mind when drafting living wills.

First, it is uncertain whether health care personnel are required to carry out the terms of a living will; conversely, those who, in good faith, act in accordance with living wills are not assured immunity from civil or criminal prosecution. No penalties are provided for the destruction, concealment, forgery or other misuse of living wills, which leaves them somewhat vulnerable to abuse. The question of whether a refusal of life-sustaining therapy constitutes suicide is unresolved, as are the insurance implications of a patient's having died as a result of a physician's withholding treatment pursuant to a living will.

Yet even in states that have not enacted legislation to recognize and implement advance directives, living wills may still have some legal effect.[55] For example, should a practitioner be threatened with civil liability or criminal prosecution for having acted in accord with such a document, it should at least serve as evidence of a patient's wishes and assessment of benefit when he or she was competent.[56] Indeed, no practitioner has been successfully subjected to civil liability or criminal prosecution for having followed the provisions in a living will,

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[53] Letter from Abigail van Buren to Joanne Lynn (Sept. 10, 1981). Ann Landers reports similar public enthusiasm. Letter from Ann Landers to Joanne Lynn (Sept. 16, 1981).

[54] For a discussion of the legal effects of living wills, *see* Luis Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 IND. L. J. 539, 552 (1969); Michael T. Sullivan, *The Dying Person—His Plight and His Right*, 8 NEW ENG. L. REV. 197, 215 (1973); Comment, *Antidysthanasia Contracts: A Proposal for Legalizing Death With Dignity*, 5 PAC. L.J. 738, 739-40 (1974); Note, *The "Living Will": The Right to Death With Dignity?*, 26 CASE W. RES. L. REV. 485, 509-526 (1976); Note, *Informed Consent and the Dying Patient*, 83 YALE L.J. 1632, 1663-64 (1974); Note, *The Right to Die*, 10 CAL. W.L. REV. 613, 625 (1974).

[55] *See* Note, *Living Wills—Need for Legal Recognition*, 78 W. VA. L. REV. 370 (1976); *See also, In re* Storar, 52 N.Y.2d 363, 420 N.E.2d 64 (1981) (on reliance on oral advance directives with burden of proof being clear and convincing evidence).

[56] *See* Kutner, *supra* note 54; Note, *The "Living Will": The Right to Death with Dignity?, supra* note 54; David J. Sharpe and Robert F. Hargest, *Lifesaving Treatment for Unwilling Patients*, 36 FORDHAM L. REV. 695, 702 (1968).

nor do there appear to be any cases brought for having acted against one.[57]

Natural death acts. To overcome the uncertain legal status of living wills,[58] 13 states and the District of Columbia have followed the lead set by California in 1976 and enacted statutes that formally establish the requirements for a "directive to physicians."[59] The California statute was labeled a "natural death" act and this term is now used generically to refer to other state statutes. Although well-intended, these acts raise a great many new problems without solving many of the old ones.

No natural death act yet deals with all the issues raised when living wills are used without specific statutory sanction. For instance, the acts differ considerably in their treatment of penalties for failing to act in accord with a properly executed directive or to transfer the patient to a physician who will follow the directive.[60] In some jurisdictions, the statutes consider these failures to be unprofessional conduct and therefore grounds for professional discipline, including the suspension of a license to practice medicine.[61] Other statutes fail to address the issue; presumably, however, existing remedies such as injunctions or suits for breach of contract or for battery are available to patients or their heirs,[62] although

[57] A UPI study, reported in *The Right to Die*, 12 TRIAL (Jan. 1976), stated that no living will had been tested in the courts. None since has come to the Commission's attention.

[58] *See* Note, *Living Wills—Need for Legal Recognition*, 78 W. VA. L. REV. 370, 377 (1976); Note, *The "Living Will": The Right to Death With Dignity?, supra* note 54, at 525-26.

[59] *See* note 47 *supra*.

[60] Like most provisions of the statutes, the requirement that the physician who refuses to comply must effectuate a transfer to another physician has not been tested. Such a transfer might at times be very difficult and a "good faith" effort might be the appropriate standard rather than the actual transfer.

[61] The California statute stipulates that a physician's failure to effectuate a binding, though not a merely advisory, directive, or to transfer the patient to another physician who will effectuate the directive of the qualified patient, shall constitute unprofessional conduct. *See* Appendix D, pp. 324-29 *infra*. The Texas statute weakens this penalty by stipulating that such a failure *may* constitute unprofessional conduct. *See* Appendix D, pp. 368-73 *infra*. The statutes of Kansas and the District of Columbia, which do not contain the binding/advisory distinction, provide that the failure to properly transfer a patient when the physician cannot comply with a valid advance directive shall constitute unprofessional conduct. *See* Appendix D, pp. 345-49, 335-40 *infra*. The statutes of the remaining states make no explicit provision for penalties for physicians who do not comply with valid advance directives or transfer patients to physicians who will effectuate the directives. *See* Table D1, pp. 310-12 *infra*.

[62] *See* Michigan House Bill No. 4492 (March 26, 1981), Appendix E, pp.

there do not appear to be any instances of such penalties being sought.

Some of the statutes attempt to provide patients with adequate opportunity to reconsider their decision by imposing a waiting period between the time when a patient decides that further treatment is unwanted and the time when the directive becomes effective. Under the California statute, for example, a directive is binding only if it is signed by a "qualified patient," technically defined as someone who has been diagnosed as having a "terminal condition." This is defined as an incurable condition that means death is "imminent" regardless of the "life-sustaining procedures" used.[63] A patient must wait 14 days after being told of the diagnosis before he or she can sign a directive, which would require a miraculous cure, a misdiagnosis, or a very loose interpretation of the word "imminent" in order for the directive to be of any use to a patient. The statute requires that when a directive is signed, the patient must be fully competent and not overwhelmed by disease or by the effects of treatment, but a study of California physicians one year after the new law was enacted found that only about half the patients diagnosed as terminally ill even remain conscious for 14 days.[64] There is an inherent tension between ensuring that dying patients have a means of expressing their wishes about treatment termination before they are overcome by

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431-37 *infra*, which provides for the appointment of an agent for medical decisionmaking and presents an approach to physician penalties that is worth considering. Section 12(2) states:

> A physician or other health care professional acting under the direction of a physician who fails to observe a refusal of medical treatment or a request for continued medical treatment by an agent shall be legally liable in the same manner and degree as would have been the case if the appointor had been capable of making the decision and had refused or requested the treatment in his or her own right under similar circumstances.

See also Bruce L. Miller, *Michigan Medical Treatment Decision Act*, in Cynthia B. Wong and Judith P. Swazey, DILEMMAS OF DYING: POLICIES AND PROCEDURES FOR DECISIONS NOT TO TREAT, G.K. Hall Med. Pub., Boston (1981) at 161.

[63] Cal. Health & Safety Code §§ 7187(e), 7191(b) (Deering Supp. 1982), Appendix D, pp. 324-29 *infra*.

[64] Note, *The California Natural Death Act: An Empirical Study of Physicians' Practices*, 31 STAN. L. REV. 913, 928 (1979). Only two of the statutes passed since California's have followed that state's lead on these provisions. Although they differ in details, both Oregon and Texas treat only those directives executed after the patient has been informed that he or she has a terminal illness as "conclusively presumptive" of the patient's desires regarding the withholding or withdrawal of life-sustaining procedures. *See* Appendix D, pp. 362-68, 368-73 *infra*.

incompetence and ensuring that people do not make binding choices about treatment on the basis of hypothetical rather than real facts about their illness and dying process. If a waiting period is deemed necessary to resolve this tension the time should be defined in a way that does not substantially undercut the objective of encouraging advance directives by people who are at risk of becoming incapacitated.

Although the California statute was inspired in part by the situation of Karen Quinlan, whose father had to pursue judicial relief for a year in order to authorize the removal of her respirator, it would not apply in a case like hers.

> The only patients covered by this statute are those who are on the edge of death *despite the doctors' efforts*. The very people for whom the greatest concern is expressed about a prolonged and undignified dying process are unaffected by the statute because their deaths are not imminent.[65]

The class of persons thus defined by many of the statutes,[66] if it indeed contains any members, at most constitutes a small percentage of those incapacitated individuals for whom decisions about life-sustaining treatment must be made. Although some statutes have not explicitly adopted the requirement that treatments may be withheld or withdrawn only if death is imminent whether or not they are used,[67] this requirement is still found in one of the most recently passed natural death acts.[68] Such a limitation greatly reduces an act's potential.

Some of the patients for whom decisions to forego life-sustaining treatment need to be made are residents of nursing homes rather than hospitals. Concerned that they might be under undue pressure to sign a directive, the California legislature provided additional safeguards for the voluntariness of their directives by requiring that a patient advocate or ombudsman serve as a witness.[69] The Commission believes that health care providers should make reasonable efforts to involve disinterested parties, not only as witnesses to the

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[65] A.M. Capron, *The Development of Law on Human Death*, 315 Annals N.Y. Acad. Sci. 45, 55 (1978).

[66] *See* state statutes for Alabama, California, Delaware, the District of Columbia, Idaho, Kansas, New Mexico, Oregon, Texas, Vermont, and Washington in Appendix D, pp. 318-49, 353-57, 362-77, 382-87 *infra*.

[67] *See* Table D1 pp. 310-12 *infra*.

[68] Del. Code Ann. tit. 16, § 2501(e) (1982), Appendix D, pp. 330-35 *infra*.

[69] The California statute, Appendix D, pp. 324-29 *infra*, refers to a patient advocate or ombudsman "as may be designated by the State Department of Aging for this purpose pursuant to any other applicable provision of law." A companion statute providing for such a service was not approved by the legislature, however, precluding residents of California nursing homes effectively from making valid directives. *See* Capron, *supra* note 65, at 56.

signing of a directive under a natural death act, but also as counselors to patients who request such a directive to ensure that they are acting as voluntarily and competently as possible. Yet statutory requirements of this sort may have the effect of precluding use of advance directives by long-term care residents, even though some residents of these facilities might be as capable as any other persons of using the procedure in a free and knowing fashion.

Paradoxically, natural death acts may restrict patients' ability to have their wishes about life-sustaining treatment respected. If health care providers view these as the exclusive means for making and implementing a decision to forego treatment and, worse, if they believe that such a decision cannot be made by a surrogate on behalf of another but only in accordance with an advance directive properly executed by a patient, some dying patients may be subject to treatment that is neither desired nor beneficial. In fact, although 6.5% of the physicians surveyed in California reported that during the first year after passage of the act there they withheld or withdrew procedures they previously would have administered, 10% of the physicians reported that they provided treatment they formerly would have withheld.[70]

In addition, there is the danger that people will infer that a patient who has not executed a directive in accordance with the natural death act does not desire life-sustaining treatment to be ended under any circumstances.[71] Yet the person may fail to sign a directive because of ignorance of its existence, inattention to its significance, uncertainty about how to execute one, or failure to foresee the kind of medical circumstances that in fact develop.[72] Unfortunately, even the explicit disclaimer contained in many of these laws—that the act is not intended to impair or supersede any preexisting common-law legal rights or responsibilities that patients and practitioners may have with respect to the withholding or withdrawing of

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[70] *Note, supra* note 64, at 938-39.

[71] McCormick and Hellegers, *supra* note 47. McCormick has since withdrawn his opposition to "living will" legislation, despite continuing concern with overtreatment of those who have not signed.

> Our experience of recent rulings by the...Courts on the need for legislative direction on these questions, and the fact that an overwhelming number of physicians, attorneys and legislation continue to believe an individual's statement has no legitimacy without a statutory enactment, force us to revise our previous opposition to this legislation.

John J. Paris and Richard A. McCormick, *Living-Will Legislation, Reconsidered*, 145 AMERICA 86, 86-87 (1981).

[72] Leon R. Kass, *Ethical Dilemmas in the Care of the Ill: II. What is the Patient's Good?*, 244 J.A.M.A. 1946, 1948 (1980).

life-sustaining procedures—does not in itself correct this difficulty.

First, the declarations about the right of competent patients to refuse "life-sustaining procedures" take on a rather pale appearance since such procedures are defined by the statutes as those that cannot stop an imminent death. (In other words, competent patients may refuse futile treatments.) Second, it is hard to place great reliance on preexisting common law rights, since had the common law established such rights there would have been no real need for the statutes. Thus, if health care providers are to treat patients appropriately in states that have adopted natural death acts, they will need the encouragement of their attorneys—backed by sensible judicial interpretation of the statutes—to read the acts as authorizing a new, additional means for patients to exercise "informed consent" regarding life-saving treatment, but not as a means that limits decisionmaking of patients who have not executed binding directives pursuant to the act.

The greatest value of the natural death acts is the impetus they provide for discussions between patients and practitioners about decisions to forego life-sustaining treatment.[73] This educational effect might be obtained, however, without making the documents binding by statute and without enforcement and punishment provisions.

Durable power of attorney statutes. Of the existing natural death acts, only Delaware's explicitly provides for the appointment of an agent for medical decisionmaking if the patient becomes incapacitated.[74] In view of the Commission's conclusion that both instruction and proxy directives are important for medical decisionmaking that respects patients' wishes, this deficiency in the other statutes constitutes a serious shortcoming. Proxy directives allow patients to control decisionmaking in a far broader range of cases than the instruction directives authorized by most existing natural death acts.

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[73] A California Medical Association study of the effects of the California Natural Death Act, conducted one year after it went into effect, emphasized that "the Act has been a positive force in encouraging patients and their families to discuss the subject of terminal illness." Murray Klutch, *Survey Result After One Year's Experience With the National Death Act*, 128 WEST. J. MED. 329, 330 (1978).

[74] Del. Code Ann. tit. 16, § 2502(b) (1982). In the 1981 legislative session in Michigan, House Bill No. 4492 contained provisions designed to authorize the appointment of an agent for medical decisionmaking. *See* Appendix D, pp. 330-35 *infra*.

Nonetheless, authority to appoint a proxy to act after a person becomes incompetent does exist in the 42 states that have laws authorizing durable powers of attorney.[75] A "power of attorney" is a document by which one person (the "principal") confers upon another person (the "agent") the legally recognized authority to perform certain acts on the principal's behalf. For instance, a person who moves to a new city and who leaves behind an automobile for someone else to sell can execute a power of attorney to permit an agent to complete the necessary legal documents in connection with the sale. In this case the power of attorney is a limited one; it gives the agent authority to perform only a specific act—the transfer of title to a particular piece of property. Powers of attorney may also be general, conferring authority on the agent to act on behalf of the principal in all matters. Such actions by agents are as legally binding on principals as if the latter had performed the acts themselves.

A power of attorney—general or limited—may be employed in making decisions not only about property but about personal matters as well, and in this role powers of attorney might be used to delegate authority to others to make health care decisions. A power of attorney, therefore, can be an advance proxy directive. Using it, a person can nominate another to make health care decisions if he or she becomes unable to make those decisions.

One barrier to this use of a power of attorney, however, is that the usual power of attorney becomes inoperative at precisely the point it is needed; a common-law power of attorney automatically terminates when the principal becomes incapacitated.[76] To circumvent this barrier, many states have enacted statutes creating a power of attorney that is "durable"—which means that an agent's authority to act continues after his or her principal is incapacitated. As a result, durable power of attorney acts offer a simple, flexible, and powerful device for making health care decisions on behalf of incapacitated patients.[77]

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[75] *See* Appendix E, pp. 389-437 *infra*.

[76] *See* RESTATEMENT (SECOND) OF AGENCY, American Law Institute Publishers, St. Paul, Minn. (1957) § 122.

[77] Virtually all the durable power of attorney statutes enacted in approximately 40 states have been modeled on three acts: (1) Virginia Code Sections 11-9.1 to .2 (1950), (2) Model Special Power of Attorney for Small Property Interests Act (Uniform Law Commissioners, 1964), and (3) Uniform Probate Code Section 5-501 to 502 (1969). In 1979, the National Conference of Commissioners on Uniform State Law promulgated a Uniform Durable Power of Attorney Act, which has been enacted in four states as of February 1983. *See* Appendix E, pp. 391-92 *infra* and note 78 *infra*.

The provisions of the Uniform Durable Power of Attorney Act are

Although not expressly enacted for the problems of incompetent patients' health care decisionmaking, the language of these statutes can accommodate the appointment of a surrogate for that purpose and nothing in the statutes explicitly precludes such a use.[78] The flexibility of the statutes allows directives to be drafted that are sensitive both to the different needs of patients in appointing proxy decisionmakers and to the range of situations in which decisions may have to be made.

The Commission therefore encourages the use of existing durable power of attorney statutes to facilitate decisionmaking for incapacitated persons, but it also recognizes the possibility for abuse inherent in the statutes. These statutes do not have rigorous procedures because they were enacted primarily to avoid the expense of full guardianship or conservatorship proceedings when dealing with small property interests.[79] Adapting them to the context of health care may require that greater procedural safeguards be provided: precisely which safeguards are needed might best be determined after more experience has been acquired. Existing durable power of attorney statutes need to be studied, therefore, as they are applied to decisionmaking for incapacitated patients facing health care decisions.

Proposed Statutes. Various concerned groups have proposed statutes that might improve upon natural death acts, by being more generally applicable and authorizing proxy designation, as well as upon durable power of attorney statutes, by providing protections and procedures appropriate to health care decisionmaking.

The Society for the Right to Die has proposed a "Medical Treatment Decision Act," which is similar to the existing natural death acts.[80] The proposal shares the narrowness of

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typical. Its basic provisions provide for the appointment of an attorney whose authority continues notwithstanding the principal's subsequent disability or incapacity (Sections 1 and 2). Other provisions protect those who engage in transactions with an attorney in fact (a proxy) by ensuring that, in the absence of the proxy knowing of the principal's death and provided the proxy acts in good faith, the authority to act is not revoked by the principal's death (Sections 4 and 5).

[78] Four states—California, Kansas, Massachusetts, and Wisconsin—have adopted the Uniform Durable Power of Attorney Act, which creates a strong presumption for conservator of person but does not establish that power. *See* Appendix E, pp. 391-92 *infra*.

[79] National Conference of Commissioners on Uniform State Laws, HANDBOOK AND PROCEEDINGS OF THE ANNUAL CONFERENCE MEETING 1964 (1964) at 273-74.

[80] Yale Law School Legislative Services Project, *Medical Treatment Decision Act*, SOCIETY FOR THE RIGHT TO DIE, New York (1981), *reprinted in* Appendix D, pp. 313-17 *infra*.

application of most such acts and makes no explicit provision for designating a proxy for medical decisionmaking.

The National Conference of Commissioners on Uniform State Laws has drafted a "Model Health Care Consent Act."[81] Despite its comprehensive title, this act does not have consent as a central concern; more correctly it is a "substitute authority to decide" act. It provides for the appointment of a health care representative to make decisions should a patient be incompetent. Although its intent to provide for proxy directives is laudable, the proposal does not resolve certain central issues. In particular, it does not specify which standard should guide a health care representative (best interests or substituted judgment). The act is also imprecise in the determination of capacity to consent. Procedures governing revocation of the appointment of a health care representative and redelegation of authority are uncertain and liable to abuse.

A national educational group called Concern for Dying has had its Legal Advisory Committee draft a "Uniform Right to Refuse Treatment Act."[82] The Act enunciates competent adults' right to refuse treatment and provides a mechanism by which competent people can both state how they wish to be treated in the event of incompetence and name another person to enforce those wishes. In terms of its treatment of such central issues as the capacity to consent and standard by which a proxy decisionmaker is to act, the Uniform Right to Refuse Treatment Act is carefully crafted and in conformity with the Commission's conclusions. Greater opportunity for review of determinations of incompetency and of proxy's decisions may be needed, however, to protect patients' self-determination and welfare.

Another proposed statute was developed by a committee of concerned citizens in Michigan. First submitted to the state legislature in 1979, their bill would have established the authority of a competent person to designate a proxy specifically for health care decisonmaking.[83] Although Michigan had a durable power of attorney statute, it was not used for health care, perhaps because many people did not know of its availability and it seemed to require a lawyer's drafting services. The proposed proxy decisionmaking bill is simple and direct, yet includes significant procedural safeguards.

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[81] *Model Health Care Consent Act* (draft), National Conference of Commissioners on Uniform State Laws, Chicago (1982), *reprinted in* Appendix E, pp. 423-28 *infra*.

[82] *Uniform Right to Refuse Treatment Act* (draft), Concern for Dying, New York (May 1982), *reprinted in* Appendix E, pp. 428-31 *infra*.

[83] Michigan House Bill 4492 (March 26, 1981), *reprinted in* Appendix E pp. 431-37 *infra; see also* Arnold S. Relman, *Michigan's Sensible "Living Will,"* 300 NEW ENG. J. MED. 1270 (1979).

General Considerations in Formulating Legislation. The Commission believes that advance directives are, in general, useful as a means of appropriate decisionmaking about life-sustaining treatment for incapacitated patients. The education of the general public and of health care professionals should be a concern to legislators, as the statutes are ineffective if unknown or misunderstood. Many of the natural death and durable power of attorney statutes are less helpful than they might be. In the drafting or the amending of legislation to authorize advance directives, a number of issues need attention.[84]

Requisites for a valid directive. Some way should be established to verify that the person writing a directive was legally competent to do so at the time. A statute might require evidence that the person has the capacity to understand the choice embodied in the directive when it is executed. The statute should clearly state whether the witnesses that are required attest to the principal's capacity or merely ensure that signatures are not fraudulent. Since such witnesses are likely to be laypeople, the standard of decisionmaking capacity they apply will rest on common sense, not psychological expertise. Furthermore, the standard they are asked to attest to may be as low as that used in wills, unless specified differently.

The principal and the prospective proxy should recognize the seriousness of the step being taken, but this will be difficult to guarantee by statute. One way to increase the likelihood that due regard is given to the subject matter would be to provide that before a directive is executed, the principal (and proxy, where one is involved) must have had a discussion with a health care professional about a directive's potential consequences, in light of the principal's values and goals. This would also help ensure that any instructions reflect a process of active self-determination on the part of the patient.

Legal effect of directives. A statute should ensure that people acting pursuant to a valid directive are not subject to civil or criminal liability for any action that would be acceptable if performed on the valid consent of a competent patient. Since directives—particularly those including instructions—may contain unavoidable ambiguities, some recognition of the need for interpretation will be needed to provide adequate reassurance for health care professionals and proxies. Some of the existing statutes speak of protection for actions taken in "good faith,"[85] which provides sensible

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[84] These considerations were developed at greater length in MAKING HEALTH CARE DECISIONS, *supra* note 2, at 155-66.

[85] Statutes of Ala., Del., Ks., N.M., Ore., Wash., in Appendices D and E, pp. 309, 389 *infra; Medical Treatment Decision Act*, Appendix D, pp. 313-17 *infra; Uniform Right to Refuse Treatment Act*, Appendix E, pp. 428-31 *infra*.

protection. Some standard of reasonable interpretation of the directive may need to be imposed, however, on an attending physician's reading of the document, lest "good faith" offer too wide a scope for discretion. Such a standard might best be developed in case law and scholarly commentary rather than in the statute itself.

The wisdom or necessity of penalties for noncompliance (fines, for example, or suspension or revocation of professional licenses[86]) depends upon the problem a statute is attempting to remedy. If health care professionals are unwilling to share responsibility with patients and, in particular, tend to overtreat patients whose physical or mental condition leaves them unable to resist, then—unless they are made legally binding—advance directives are unlikely to protect patients who want to limit their treatment. On the other hand, if health care professionals are simply unsure of what patients want, or if they are willing to share decisionmaking responsibility but are apprehensive about their legal liability if they follow the instructions of a person whose decisionmaking capacity is in doubt, then the threat of penalties would be unnecessary and potentially counterproductive by fostering an adversarial relationship between patient and provider. The evidence available at present does not clearly support substantial penalties.[87]

Proxy's characteristics and authority. Several special questions arise in the context of health care concerning who may act as a proxy and what the proxy may do. A proxy should have the decisionmaking capacity needed for a particular health care situation. The criteria for determining presence of adequate capacity in a proxy are the same as for patients themselves.[88]

Statutes might limit who may serve as proxy so as to avoid the appointment of anyone likely to act upon interests that are adverse to a patient's. In some natural death statutes, the criteria for witnesses explicitly exclude anyone financially involved (as debtor, creditor, or heir) with the patient.[89] If a similar restriction were applied to proxies, this might eliminate virtually everyone who cares about the patient, however. Special restrictions on who may be a proxy may be warranted for patients in long-term care and psychiatric institutions, though the appropriate form of such conditions is uncertain.

In certain circumstances a proxy may be temporarily or permanently unable or unwilling to serve as a substitute

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[86] *See* state statutes for California, the District of Columbia, Kansas, Oregon, and Texas, Appendix D, pp. 324-29, 335-40, 345-49, 362-73 *infra*.

[87] There are no cases known to the Commission of penalties being imposed under any of the natural death acts that provide for them.

[88] *See* pp. 121-26 *supra*.

[89] *See, e.g.*, the statute for California, Appendix D, pp. 324-29 *infra*.

decisionmaker. When that occurs, alternate proxies could be limited to people who were named by the principal in an original or amended directive; or, alternately, a proxy could be allowed to delegate his or her authority to another person of the proxy's choosing.[90] This issue might be affected by whether either the original or a substitute proxy was a close relative of the patient, as opposed to a stranger.

Since the proxy stands in the shoes of the patient and is expected to engage in a comparable decisionmaking process, logically the proxy should have access to the patient's medical record. Yet it may sometimes be advisable to allow the proxy's access to be limited to the information needed for the health care decision at hand, in order to respect the patient's privacy.

Any directive issued by a competent person, and especially an instruction directive, can use the Commission's preferred standard for surrogate decisionmaking—substituted judgment.[91] The interpretation of such a directive should ordinarily lie with the surrogate decisionmaker, particularly in the case of a proxy designated by the patient. Provision may have to be made for an administrative mechanism to decide situations in which a health care professional challenges a proxy's decision on the ground that it is based on neither a reasonable interpretation of the patient's instructions nor on the patient's best interests.

Administrative aspects. Several procedural concerns probably need to be addressed in any statute for advance health care directives. A statute needs to specify how a directive becomes effective. Some of the natural death acts, as already mentioned, require that a directive be executed after the patient has been informed of a diagnosis, so that the person's instructions are arrived at in the context of the actual, rather than the hypothetical, choices to be made.[92] Some statutes also provide that the directive be renewed every few years so that the signatory can reconsider the instructions or designation in light of changed circumstances or opinions.[93]

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[90] For example, the *Model Health Care Consent Act*, Appendix E, pp. 423-28 *infra*, provides for a limited delegation of power by some individuals, authorized to consent to health care for another. The only proxies who may delegate their decisional authority are family members. Nonfamily health care representatives, who may be appointed according to the terms of the Act, are not authorized to delegate their decisional authority. All delegations must be in writing, and unless the writing so specifies, no further delegation of decisional authority is permitted. Any delegated authority terminates six months after the effective date of the writing.

[91] *See* pp. 132-34 *supra*.

[92] *See* Table D1, pp. 310-12 *infra*.

[93] *Id.*

The trigger for a valid directive becoming operative also needs to be specified. A statute may leave that question to the document itself, to be specified by the person executing the directive, or it may provide that a particular event or condition brings the document into play. In either case, the triggering event will require both a standard for action and a specification of who will determine that the standard is met. For example, a directive may become operative when a physician makes a particular prognosis ("terminal illness") or determines that a patient lacks decisional capacity regarding a particular health care choice.

Provision must be made for the process and standard by which a document can be revoked. The value of self-determination suggests that as long as the principal remains competent, he or she should unquestionably have the power to revoke a directive. But what about an incompetent (incapacitated) person? The natural death acts have uniformly provided that *any* revocation by a principal negates a directive.[94] In the context of foregoing life-sustaining treatment, that result may be sensible, since it would generally seem wrong to cease such treatment based upon a proxy's orders when a patient, no matter how confused, asks that treatment be continued.[95] In other circumstances, however, allowing revocations by an incompetent patient could seriously disrupt a course of treatment authorized by a proxy. When the proxy intends to override the principal's contemporaneous instructions because the incompetent principal is contradicting earlier competent instructions and/or acting contrary to his or her best interests, the question of whether to follow the proxy or the principal may have to be resolved by an independent review.

In general, when disputes arise about such things as the choice made by a proxy or an attempted revocation by an apparently incapacitated principal, a review process will be an important safeguard for the patient's interests. In some circumstances the review mechanism need only judge whether the decisionmaking process was adequate. In other circumstances it may be advisable to review the health care decision itself and the application of the appropriate decisionmaking standard. In the absence of a special provision in the statute,

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[94] Appendix D, pp. 309-87 *infra*.

[95] An exception might be the patient who knows that foregoing a treatment is likely to bring about a period of incompetence prior to death, during which the patient might ask for the treatment. If such a patient wants to bind all parties concerned—health care professionals, family, and patient—in a promise to act in accord with the preferences expressed by the patient while competent, such a request might be honored. *See* Gail Povar, *Case #11*, in James F. Childress, WHO SHOULD DECIDE? PATERNALISM AND HEALTH CARE, Oxford Univ. Press, New York (1982) at 224-25.

questions of this sort should lead to intrainstitutional review and, as needed, to judicial proceedings.[96]

Conclusions. The Commission commends the use of advance directives. Health care professionals should be familiar with their state's legal mechanisms for implementing advance directives on life-sustaining treatment and encourage patients to use these resources. In particular, practitioners can alert patients to the existence of durable power of attorney devices (in states where they exist) and urge them to discuss their desires about treatment with a proxy decisionmaker. In states without applicable legislation, practitioners can still inform their patients of the value of making their wishes known, whether through a living will or more individual instructions regarding the use of life-sustaining procedures under various circumstances.

Institutions concerned with patient and practitioner education have an important role to play in encouraging patients to become familiar with and use advance directives, and in familiarizing practitioners with the ethical and practical desirability of their patients using these mechanisms. Finally, legislators should be encouraged to draft flexible and clear statutes that give appropriate legal authority to those who write and rely upon advance directives. Such legislation needs to balance the provisions aimed at restricting likely abuses and those intended to allow flexibility and individuality for patients and proxies.

Procedures for Review of Decisionmaking

The responsibility for ensuring that decisionmaking practices are of high quality falls first to the attending physician. No one else is regularly in as good a position to enhance and assess decisionmaking capacity, to inform the patient, to learn the patient's priorities, to designate an appropriate surrogate decisionmaker, and to know when other assistance is needed. Furthermore, helping patients consider how their health affects their lives is a traditional responsibility of physicians. However, the skills necessary are varied and the situations complex. To assign primary responsibility to physicians does not mean that there will be no need to involve others. On the contrary, physicians ordinarily need the assistance of family members, nurses, therapists, and others to help inform and communicate with a patient. And when decisions are serious and errors are irremediable—as is often the case in foregoing life-sustaining treatment—there is additional need for review and appeal, both as to general practices and in specific cases.

[96] *See* pp. 153-70 *infra*.

Judicial Review. The Commission concludes that ordinarily a patient's surrogate—whether designated through judicial proceedings or informally—should have the legal authority to make decisions on behalf of an incapacitated patient.[97] Decisions made by such surrogates and physicians are now rarely subjected to court review. Only in unusual cases, for example when there is a conflict among next-of-kin[98] or when the surrogate chooses a highly unusual course of treatment or nontreatment,[99] do health care providers refuse to honor a surrogate's decision to forego treatment. When this occurs, there are currently two alternatives: either the physician's recommended treatment will be continued and the surrogate will be effectively disenfranchised, or the surrogate or a provider will seek judicial resolution of the dispute.

Increasingly, health care providers have felt compelled to seek judicial review of surrogates' decisions to forego life-sustaining treatment. Some providers have sought review because they have disagreed with the surrogate's decision,[100] but others have done so even when they were comfortable with the decision but feared criminal or civil liability for foregoing treatment,[101] especially when it seemed uncertain that the individual acting as surrogate was properly authorized to do so.[102]

Since only a handful of jurisdictions have had occasion to address the issue (and since legislative guidance is also sparse), it is uncertain whether judicial proceedings must always be initiated in order to withhold or withdraw life-sustaining treatment from incompetent patients. Given that treatments necessary to keep unconscious patients alive for long periods of time had been used for a number of years prior

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[97] *But see, In re* Roe, 421 N.E.2d 40 (Mass. 1981) (decision of court-appointed surrogate to administer neuroleptic medications to ward must be reviewed and approved by court).

[98] *See, e.g., In re* Nemser, 51 Misc.2d 616, 273 N.Y.S.2d 624 (Sup. Ct. 1966).

[99] *See, e.g.*, Custody of a Minor, 393 N.E.2d 836 (Mass. 1979); *In re* Hoffbauer, 47 N.Y.2d 648, 419 N.Y.S.2d 936, 393 N.E.2d 1009 (1979).

[100] *See, In re* Storar, 52 N.Y.2d 363, 420 N.E.2d 64, 68-69 (1981); Severns v. Wilmington Medical Center, Inc., 421 A.2d 1334 (Del. 1980); *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

[101] *See, e.g.*, Severns v. Wilmington Medical Center, Inc., 421 A.2d 1334 (Del. 1980); *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976); Eichner v. Dillon, 426 N.Y.S.2d 527 (App. Div. 1980), *modified by, In re* Storar 420 N.E.2d 64 (N.Y. 1981).

[102] *See, e.g., In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976). Judges have been involved in other cases when the patient was already a ward of the state or lacked family members or friends to serve as a surrogate. *See, e.g.*, Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417 (Mass. 1977); Custody of a Minor, 393 N.E.2d 836 (Mass. 1979).

to *Quinlan*, it is remarkable that this first legal case raising most of the issues concerning decisionmaking for patients lacking capacity did not arise until 1975.[103] Clearly, decisions about this sort of care were being made routinely without formal court review. Indeed, the Supreme Court of New Jersey in *Quinlan* recited at some length the testimony of a physician witness indicating that problems such as these had long existed and ordinarily had been handled without the involvement of people or social institutions other than the patient's family, physicians, and possibly hospital administrators. The witness endorsed this practice, which he termed "judicious neglect":

> Don't treat this patient anymore, it does not serve either the patient, the family or society in any meaningful way to continue treatment with this patient.
>
> ...No physician that I know personally is going to try and resuscitate a man riddled with cancer and in agony and he stops breathing. They are not going to put him on a respirator....I think that would be the height of misuse of technology.[104]

Thus, one of the things the *Quinlan* case did was to bring these issues into the open for public debate and, in some cases, for a more public resolution through the judicial process.

In its report on informed consent, the Commission endorsed the general approach to decisionmaking for incapacitated patients advocated by the New Jersey Supreme Court in *Quinlan*.[105] This approach involves leaving decisional authority in the hands of an incompetent patient's guardian, in consultation with a hospital "ethics committee."[106] In strong language,

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[103] Of course, the *Quinlan* case did not arise in legal vacuum. The New Jersey court used precedents concerning such issues as religious beliefs, state interests, the right of privacy, and the standards of the medical profession in crafting its opinion. *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922 (1976).

[104] 355 A.2d at 657, quoting an expert witness at trial, Dr. Julius Korein. The court in *Saikewicz* referred to similar practices:

> The force and impact of [the medical profession's interest in the maintenance of its ethical integrity] is lessened by the prevailing medical ethical standards...[which] does not, without exception, demand that all efforts toward life prolongation be made in all circumstances. Rather...the prevailing ethical practice seems to be to recognize that the dying are more often in need of comfort than treatment.

Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 426 (Mass. 1977).

[105] *See, New Jersey Guidelines for Health Care Facilities to Implement Procedures Concerning the Care of Comatose Non-Cognitive Patients, reprinted in* Appendix G, pp. 463-66 *infra.*

[106] Prior to the *Quinlan* case, the most well-known use of such

the court specifically eschewed judicial review of such decisions:

> We consider that a practice of applying to a court to confirm such decisions would generally be inappropriate, not only because that would be a gratuitous encroachment upon the medical profession's field of competence, but because it would be impossibly cumbersome.[107]

Two other courts have similarly discouraged routine court review.[108]

By contrast, the Supreme Judicial Court of Massachusetts, in a succession of cases, has explicitly rejected the decision-making method advocated by the New Jersey Supreme Court and instead established judicial review of decisions made by physicians, in conjunction with family members or legal guardians, as the rule rather than the exception. Instead of

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committees was in Seattle, where community representatives helped select among candidates for dialysis, at a time when the treatment was novel and not widely available. Shana Alexander, *They Decide Who Lives, Who Dies: Medical Miracles and a Moral Burden of a Small Town*, 53 LIFE 102 (Nov. 8, 1962). Originally, "social worth" criteria provided a basis for the committee's selection process. "The patient's 'marital status,' 'net worth,' 'occupation,' and 'past performance and future potential' were the types of social worth criteria that the committee members avowedly considered....The specific, often unarticulated indicators that were used reflected the middle-class American value system shared by the selection panel." Renée C. Fox and Judith P. Swazey, THE COURAGE TO FAIL, Univ. of Chicago Press, Chicago (1974) at 246. The committee eventually abandoned its "social worth" criteria in favor of professionally evaluated psychological assessments—"evidence of its members' profound disquiet at having to 'play God.'" *Id.* at 268.

The court assumed that such committees exist and quoted with approval a law review article by a physician that stated that "many hospitals have established an Ethics Committee composed of physicians, social workers, attorneys, and theologians,...which serves to review individual circumstances of ethical dilemmas and which has provided much in the way of assistance and safeguards for patients and their medical caretakers." *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 668, *cert. denied* 429 U.S. 922 (1976) (quoting Karen Teel, *The Physician's Dilemma: A Doctor's View: What The Law Should Be*, 27 BAYLOR L. REV. 6, 8-9 (1975)). *See also* Severns v. Wilmington Medical Center, Inc., 421 A.2d 1334, 1338 (Del. 1980).

[107] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 669, *cert. denied*, 429 U.S. 922 (1976).

[108] *See, In re* Storar, 52 N.Y.2d 363, 420 N.E.2d 64, 74 (1981) ("Neither the common law nor existing statutes require persons generally to seek prior court assessment of conduct which may subject them to civil and criminal liability"); Severns v. Wilmington Medical Center, Inc. 421 A.2d 1334 (Del. 1980).

regarding judicial review as a "'gratuitous encroachment' on the domain of medical expertise," this court

> take[s] a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent....Rather, such questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility ...and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted.[109]

The court suggested that although courts are not bound by recommendations of ethics committees, they may consider the deliberations of such groups, as well as taking testimony from medical experts.[110]

The models of decisionmaking procedures for incompetent patients derived from the opinions of the Massachusetts and New Jersey courts are quite different. The norm in Massachusetts—judicial decisionmaking with medical expertise not playing a decisive role[111]—is the exception in New Jersey,

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[109] Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 434-35 (Mass. 1977).

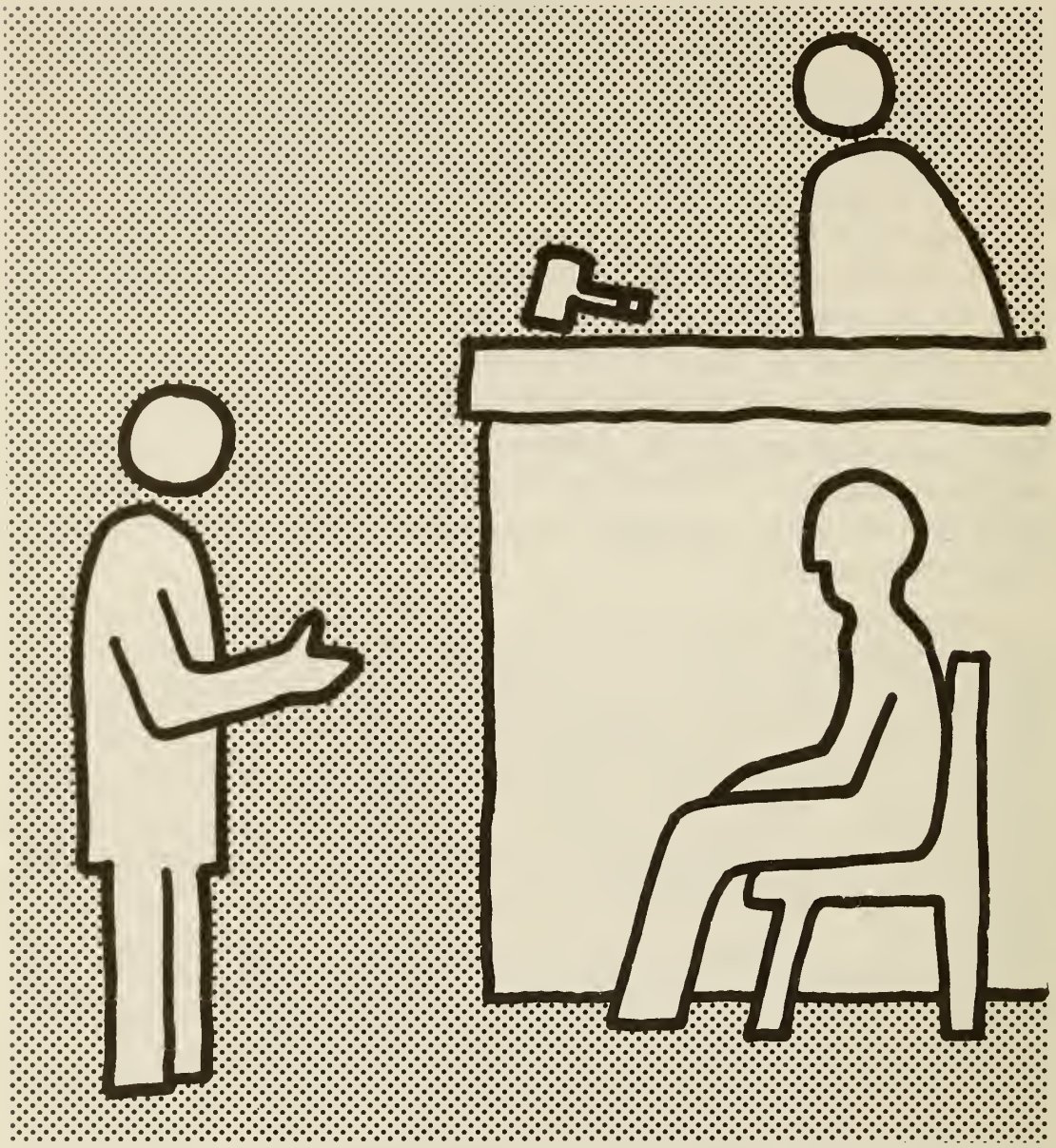
[110] *Id.* at 434.

[111] The Massachusetts Supreme Judicial Court and the Court of Appeals have both provided additional guidance about the full scope of *Saikewicz*. Prior judicial approval of all decisions to forego life-sustaining treatment is not always necessary, even in Massachusetts. The Supreme Court mentioned in *Spring* that "We are not called upon to decide what combination of circumstances makes prior court approval necessary or desirable, even on the facts of the case before us," which certainly suggests that at least some cases do not require such approval. *In re* Spring, 405 N.E.2d 115, 121 (Mass. 1980).

In *Dinnerstein*, 380 N.E. 2d 134 (Mass. App. 1978), the Court of Appeals held that judicial permission was not necessary to enter a do not resuscitate order in the medical record of an irreversibly terminally ill 67-year-old and severely demented person, and distinguished the need for judicial approval of withholding treatment in *Saikewicz* on the ground that Saikewicz's proposed treatment was reasonably expected to bring about a substantial remission of symptoms. By contrast, in the event of a cardiac arrest, Dinnerstein's situation would still be hopeless.

Custody of a Minor, 385 Mass. 697, 434 N.E.2d 601 (1982), also involved a hopelessly ill patient—a several month-old child with a life expectancy of no more than a year or two. In that case, the Massachusetts Supreme Judicial Court also permitted the entry of a DNR order but held, contrary to *Dinnerstein*, that court approval was necessary, because Mrs. Dinnerstein had a "loving family with whom

where decisionmaking by medical practitioners in conjunction with family members is routine, with resort to judicial review only in unusual, undefined circumstances.



The regular reliance on advance judicial review advocated in the Massachusetts decisions has sparked a debate about the relative costs and benefits of having courts rule on decisionmaking by surrogates for incapacitated patients.[112] A prominent defender of court involvement claims that "decisions [on behalf of incompetent patients] which are made on the same set of facts will differ from day to day and from doctor to doctor [because] few doctors have worked out principles of

physicians may consult." *Id.* at 608. But the minor here was a baby, abandoned and under the supervision of a public welfare agency. Thus, the Massachusetts court would seem to hold that, when treatment is likely to yield only brief extension of life and a caring family is available, court approval is not necessary.

[112] *See, e.g.*, H. Richard Beresford, *The Role of Judges in Life/Death Decisions for the Neurologically Impaired*, 4 ANNALS NEUROL. 463, 464 (1978); Lee J. Dunn, Jr., *The Eichner/Storar Decision: A Year's Perspective*, 10 L., MED. & HEALTH CARE 117 (1982).

decisionmaking that will survive even the most rudimentary criticism."[113]

Certain aspects of the judicial process do commend it for use in place of such variable decisionmaking. First, the judicial process is a public one. Judges' actions are subject to scrutiny by the public, the press, and legal scholars. Second, judicial decisionmaking is (ideally, at least) principled—with like cases decided alike and pains taken to develop reasoned bases for decisions. Third, the judicial process seeks impartiality by applying rules of evidence and by using disinterested decisionmakers. Finally, the adversarial nature of the process seeks to render a full and fair hearing by encouraging proponents of opposing positions to bring evidence and to present arguments before a neutral judge.[114]

On the other hand, judicial review in such cases is costly in terms of time and expense[115]; it can disrupt the process of providing care for the patient, since medical decisionmaking is evolutionary rather than static; it can create unnecessary strains in the relationship between the surrogate decisionmaker and others, such as the health care providers, who may be forced into the role of formal adversaries in the litigation; and it exposes ordinarily quite private matters to the scrutiny of the courtroom and sometimes even to the glare of the public communications media.[116]

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[113] Charles H. Baron, *Medical Paternalism and the Rule of Law: A Reply to Dr. Relman*, 4 Am. J. L. & Med. 337, 349 (1979).

[114] At times, courts may not be able to maintain a claim of distinterestedness. Rather, there is a risk that judges will have to rely on their personal preferences in an area without well-established law. *See* Leslie S. Rothenberg, *The Empty Search for an Imprimatur, or Delphic Oracles are in Short Supply*, 10 L., Med. & Health Care 115 (1982). *See also* John J. Paris, *Terminating Treatment for Newborns: A Theological Perspective*, 10 L., Med. & Health Care 120, 122 (1982). Paris comments on a judge who saves the life of an adult Jehovah's Witness by ordering tranfusions because the judge felt he could not bear being responsible for the death, but who did not take as seriously that person's belief that thereby she lost everlasting life.

[115] The Brother Fox case (*Eichner v. Dillon*) continued long past the patient's death, which occurred despite vigorous treatment. Nevertheless, his medical care during the legal battle cost $87,000 and the legal costs before his death were $20,000. Paris, *supra* note 114. A similar committee was mandated in *Eichner v. Dillon*, but this was overturned by the appeal to the state's highest court, which felt that such a mechanism required legislation. Eichner v. Dillon, 426 N.Y.S.2d 517, 550 (App. Div. 1980) *modified in, In re* Storar, 420 N.E.2d 64, 74 (N.Y. 1981).

[116] *See also, In re* Application of Lydia Hall Hospital, No. 23730 (Sup. Ct. Nassau Cty., N. Y., Oct. 22, 1982). In this case, the family of Peter Cinque, a patient who gave explicit, competent, and informed advance directives to discontinue life-sustaining treatment, has threatened the hospital that went to court seeking to overturn his directive.

These costs may be justifiable if wiser decisions are made and patients are provided with additional protection from harm. Frequently, however, the process of judicial review in these cases is merely a formality. Judges may feel that they are unable to add much to the decisions already worked out among those most intimately involved, particularly in cases that are brought simply to obtain judicial sanction for a course of conduct on which all are agreed.[117] Rather than examining questions that courts are accustomed to addressing, such as whether the particular surrogate should be disqualified because of a conflict of interest, the question typically addressed is whether the particular treatment chosen is the right one. Since an answer to this question would normally require substantial understanding of the patient's evolving medical condition and options, which the courts lack, they may simply defer to the recommendation of the treating physicians.

The Commission nevertheless believes there are enough possibilities for error in the process of decisionmaking for incapacitated persons by families and practitioners that this process should sometimes be reviewed, even though routine judicial oversight is neither necessary nor appropriate. The task of ensuring good decisionmaking about life-sustaining treatment will thus fall to the institutions that provide care for incapacitated dying patients. This responsibility can properly be seen as an extension of the well-recognized institutional responsibility to ensure that the well-being of such patients is promoted in other respects.

Intrainstitutional Review and the Role of Ethics Committees

Current structures and functions. The procedures that institutions establish to promote effective decisionmaking for incapacitated individuals can serve a number of specific functions.

- They can review the case to confirm the responsible physician's diagnosis and prognosis of a patient's medical condition.
- They can provide a forum for discussing broader social and ethical concerns raised by a particular case; such bodies may also have an educational role, especially by teaching all professional staff how to identify, frame, and resolve ethical problems.
- They can be a means for formulating policy and guidelines regarding such decisions.
- Finally, they can review decisions made by others (such as physicians and surrogates) about the treat-

[117] *See* Rothenberg, *supra* note 114.

ment of specific patients or make such decisions themselves.

This diversity of approaches is exhibited in the current variety of institutional bodies. One philosopher described his hospital's "Ethics Consultation Service" on which he served as having begun as an informal group of interested persons.[118] "Ethical conferences" that can be convened at any time by any physician or nurse who desires to discuss a possible withholding of life-sustaining treatment have been established in one European hospital.[119] A large community hospital in Washington, D.C., has experimented with regularly scheduled meetings within hospital units, at which patient care situations (including ethical issues) are discussed by hospital staff.[120] Other institutions have experimented with ad hoc groups constituted to be especially responsive to the needs of a particular patient.[121]

The institutional body most often mentioned in decisionmaking contexts is the ethics committee,[122] which is sometimes a continuing committee integrated into the institution's administrative structure and other times independent of it. The prominence of ethics committees as an institutional response to problems with decisionmaking is partly attributable to the important role assigned to them by the New Jersey Supreme Court in the *Quinlan* case.[123] Yet a national survey done for the Commission found that less than 1% of all hospitals—and just 4.3% of the hospitals with over 200 beds—have such committees.[124] Because many of the same concerns are likely to arise in connection with any form of intrainstitutional review, the

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[118] Benjamin Freedman, *One Philosopher's Experience on an Ethics Committee*, 11 HASTINGS CTR. REP. 20 (April 1981).

[119] Gerhard Stalder, *Ethical Committees in a Pediatric Hospital*, 136 EUR. J. PED. 119, 121 (1981).

[120] Information included in material obtained from Greater Southeast Community Hospital, Washington, D.C., especially its description of its "Collaborative Practice Committees" (June 1980).

[121] *See* Mitchell T. Rabkin, Gerald Gillerman, and Nancy Rice, *Orders Not to Resuscitate*, 295 NEW ENG. J. MED. 364, 365 (1976). *See generally* Kathi Esqueda, *Hospital Ethics Committees: Four Case Studies*, 7 THE HOSPITAL MEDICAL STAFF 26, 30 (Nov. 1978); Carol Levine, *Hospital Ethics Committees: A Guarded Prognosis*, 7 HASTINGS CTR. REP. 25, 27 (June 1977); Ronald Sullivan, *Hospitals Turn to Philosophers on Life Issues*, N.Y. TIMES, Mar. 19, 1982, at A-1.

[122] This report uses "ethics committees" to mean those committees that have the potential to become involved in decisionmaking in particular patient's cases.

[123] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976).

[124] *See* Stuart Youngner *et al., A National Survey of Hospital Ethics Committees*, Appendix F, pp. 443-57 *infra*. In a 1978 survey of Catholic hospitals, 27% responded that they had established medical-moral committees, though it is not clear that they could be involved in

Commission decided to consider the kinds of structures and functions that institutions have already given these committees.

The first issue of concern is the appropriate function of ethics committees.[125] They might be merely prognosis review committees, a role the New Jersey Supreme Court suggested in *Quinlan* when it assigned to the ethics committee the task of agreeing or disagreeing with the responsible attending physicians' determination "that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive, sapient state."[126] This essentially medical function has confused subsequent discussions of ethics committees, since there is little (if anything) distinctly "ethical" about the judgment the court asked the committee to make. "Ethics committees" established solely to confirm prognoses might better be called "prognosis review committees."[127]

Some health care institutions have primarily consultative ethics committees. In this capacity, they are available to discuss the broader ethical and social concerns of interested parties, especially as they bear on the decision to be made in a particular case, and to provide advice on request. Some

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particular cases. Letter from J. Stuart Showalter, The Catholic Health Association of the United States, to Joanne Lynn (Nov. 17, 1982).

[125] *See generally* Harold L. Hirsch and Richard E. Donovan, *The Right to Die: Medico-Legal Implications of In re Quinlan*, 30 Rutgers L. Rev. 267, 273-286 (1977); Levine, *supra* note 121; Robert M. Veatch, *Hospital Ethics Committees: Is There a Role?*, 7 Hastings Ctr. Rep. 22 (June 1977).

[126] *In re* Quinlan, 70 N.J. 10, 355 A.2d 647, 671, *cert. denied*, 429 U.S. 922 (1976).

[127] The committees described in the guidelines that were subsequently promulgated by the responsible New Jersey State agencies were indeed labeled "prognosis committees." *Guidelines for Health Care Facilities to Implement Procedures Concerning the Care of Comatose Non-Cognitive Patients, reprinted in* 74 J. Med. Soc. N.J. 35 (April 1977) and *in* Appendix G, pp. 463-66 *infra*. Alfonso A. Navarez, *Jersey Adopts Plan on Patients in Coma*, N.Y. Times, Jan. 26, 1977, at A-1.

> New Jersey, however, understandably remains confused over the proper role of such a committee. At the Morris View Nursing Home, for example, where Karen Quinlan is currently a patient, an ethics committee was formed when the nursing home knew she would be coming there. It consists of a physician, an attorney, two clergyman, a social worker, and the chairman, who is also Chairman of the Morris County Welfare Board, which manages the nursing home. This committee apparently sees itself not as a "prognosis committee" but as a committee to deal with "ethical issues."

George J. Annas, *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*, in Doudera and Peters, *supra* note 40, at 28, 49 n.34.

advocates of ethics committees as primarily consultative bodies have been adamant that such groups should not themselves make decisions. As one philosopher involved in a consultative ethics committee put it: "The job of the group is to provide a forum in which professionals can discuss their views regarding a particular case. The one overriding theme of our meetings has been: 'we make no decision.'"[128] Even ethics committees that see their purpose as primarily consultative differ regarding the groups they counsel and support. The Commission's study found that well over half the committees in existence aided physicians in this way, while only slightly more than one-quarter counseled and supported patients and families.[129]

Ethics committees may have an important educational role. The Commission's study revealed that heads of ethics committees felt the groups were generally less effective in educating professionals about issues relevant to life-support decisions than about other areas.[130] Nevertheless, experts testifying before the Commission emphasized several educational roles that the more well established ethics committees play.[131] First, in ethics committees with a diverse membership of physicians, nurses, other professionals, and laypeople, discussions allow the various members to share perspectives and views, which can lead to better decisions regarding the treatment of the incapacitated. Of particular importance here is the way ethics committees can expose the actual decisionmakers in a hospital setting to various ethical and social considerations.[132]

Second, over a period of years ethics committees may provide a setting for people within medical institutions to become knowledgeable and comfortable about relating ethical principles to specific decisions. Third, presenting a number of issues through actual cases that receive institutional attention is likely to underscore the seriousness of the issues involved, the possibility of better and worse resolutions, and the obligations of all to address the issues responsibly. Finally, ethics committees may serve as a focus for community discussion and education, which is likely to stimulate thought beyond issues of incompetence to a consideration of more general bioethical issues.

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[128] Freedman, *supra* note 118, at 20-21.

[129] Table F3, p. 451 *infra*.

[130] Appendix F, pp. 447-48 *infra*.

[131] Testimony of Dr. Ronald Cranford, transcript of 21st meeting of the President's Commission (June 10, 1982) at 18, 39.

[132] Cynthia B. Cohen, *Interdisciplinary Consultation on the Care of the Critically Ill and Dying: The Role of One Hospital Ethics Committee*, 10 Crit. Care Med. 776 (1982).

The Commission's study revealed that one stated purpose of almost half the ethics committees is to set ethical and social policy for the care of critically ill persons.[133] Although some institutions have combined this function with case management review and advice,[134] questions have been raised about the appropriateness of assigning two such apparently dissimilar tasks to the same group.[135]

Another function of ethics committees is to review certain decisions made by the family of an incapacitated person and his or her practitioner. In its review, the committee would seek to ensure that the interests of all parties, especially those of the incapacitated person, have been adequately represented, and that the decision reached lies within the range of permissible alternatives. The Commission believes that this review function—which more than half the ethics committees classified both as a stated purpose and as their actual role[136]—deserves serious consideration as a way for institutions to discharge their responsibilities to promote the well-being of incapacitated patients. When ethics committees serve as reviewers, they do not supplant the principal decisionmakers for incapacitated persons (that is, families and practitioners) but they do provide for efficient review without regularly incurring the liabilities of judicial review. (They can however, ensure that appropriate cases go to court.)

Finally, ethics committees might be actual decisionmakers.[137] The Commission's study revealed that fewer than 20% of the committees classified the making of final decisions about life support as a stated purpose, while slightly more than 30% classified this as an actual function.[138] As discussed earlier, the Commission believes that health professionals and the surrogate for an incapacitated person should be the primary decisionmakers. Regularly assigning to ethics committees the task of making decisions regarding life-sustaining treatment could undermine the recognition of obligations by those who should be principally responsible. It should be avoided, therefore, though in unusual circumstances a decision might be sought from, and appropriately given by, a committee.

The resolution of many issues concerning the structure and composition of ethics committees depends upon the functions

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[133] Table F3, p. 451 *infra*. One reported committee considers only terminally ill patients. Cohen, *supra* note 132.

[134] Esqueda, *supra* note 121, at 27.

[135] Levine, *supra* note 121, at 27.

[136] Table F3 p. 451 *infra*.

[137] Usually committees are seen as having a role in care of only current patients. Abigail Kuzma recommends that such committees screen and counsel applicants for admission to hospice, Note, *Hospice: The Legal Ramification of a Place to Die*, 56 IND. L.J. 673, 699 (1980-1981).

[138] Table F3, p. 451 *infra*.

assigned to such committees, and rests on the kind of information that can be obtained only with actual experience. Nevertheless, there are some general questions that need to be addressed in deciding whether ethics committees are an appropriate way for institutions to discharge their responsibilities.

Unresolved issues. Ironically, the very fact that ethics committees will probably be less formal and burdensome than judicial review in any particular case may cause their total impact on the health care system to be excessively burdensome. This could occur if the apparent accessibility of ethics committees was to lead to routine review of an ever larger number and wider range of medical decisions than would previously have had judicial review. If the existing process of decisionmaking, which is largely private and unreviewed, has been appropriate and has resulted in decisions that are in the aggregate as "good" as those arrived at by an ethics committee, then creating committees will complicate the total process, not improve it. Review might well be of no greater quality if, as sometimes occurs, removing responsibility from a single individual, such as the attending physician, to a larger group tends to diffuse it so that no one person feels personally responsible for the choices being made.[139] Concerns have also been raised that ethics committees will simply act either as rubber stamps for decisions made by others or as debating forums.[140]

Another issue that needs to be clarified is who has the right and responsibility to establish and appoint members to the ethics committees in health care institutions. This is a matter that should be of concern to such organizations as the American Hospital Association and the Joint Commission on the Accreditation of Hospitals. Although the exact nature of the committees may vary with the nature of the institutions in

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[139] George J. Annas, *In re Quinlan: Legal Comfort for Doctors*, 6 HASTINGS CTR. REP. 29, 30-31 (June 1976).

[140] *Id. See also*:

> Treatment guidelines are useful only insofar as they serve to clarify the prognosis and likely outcomes of various treatments so that the guardian or next of kin can make an informed decision....As long as such guidelines serve as a means of generating information for competent patients, guardians, or next of kin to make the best decision they can, the guidelines are useful. But if they serve to validate the status quo of removing such decisions from the responsible parties and reserving it to the physician or staff they overstep their own proper role and work against the patient.

Thomas A. Shannon, *The Withdrawal of Treatment: The Costs and Benefits of Guidelines*, in Thomas A. Shannon, BIOETHICS, Paulist Press, Ramsey, N.J. (rev. ed. 1981) at 219.

which they function, they must have a firm institutional footing.[141] Since more than one ethics committee may be established in large, multispecialty hospitals (perhaps with a division of committees according to their different functions or different patient populations), clear guidelines should be formulated for determining which cases are to be reviewed by each group. Institutions have experimented with different methods of selecting ethics committee members, including selection by the hospital's director on nomination from a committee of staff representatives or by a small interested group who initiated interest in the ethics committee.[142] The desirability of possible selection methods needs to be assessed.

In thinking about the appropriateness of ethics committees, consideration should be given to whether their composition reflects their function. A committee serving exclusively as a prognosis review group might justifiably be staffed exclusively by physicians, whereas such a group would be less appropriate as a forum for consideration of ethical issues. The Commission's study found that physicians and clergy are especially well represented on existing ethics committees; administrators, nurses, and attorneys are moderately well represented; few committees include social workers and laypeople.[143] The Commission believes that institutions should consider seriously the advantages of a diverse membership. First, having individuals from many different specialties, as well as those without professional specialization, can minimize the tendency to take the committee's task as essentially technical. Second, diversity can prevent ethics committees from becoming uncritically accepting of, or adverse to, the view of any one professional or social group.[144] Finally, since one of the central functions of ethics committees may be to advise patients, families, and practitioners who are trying to make informed decisions, many different perspectives should be available to those who seek the committee's guidance.

The question of how frequently ethics committees should meet and what form their deliberations should take also depends upon their designated functions. The capacity to deliberate on short notice, which is necessary to achieve reasonably prompt review, is more likely to be possible if it is recognized that not every member of the committee need be present at every meeting. Subcommittees with areas of special interest may well develop; if so, a meeting of the members of such smaller groups may suffice. Regarding the form of their

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[141] Testimony of John A. Robertson, transcript of 21st meeting of the President's Commission (June 10, 1982) at 177.

[142] Esqueda, *supra* note 121, at 27-28.

[143] Table F4, p. 452 *infra*.

[144] Cohen, *supra* note 132, at 778.

deliberations, the members of Morris View Nursing Home's ethics committee (which was established primarily in response to the *Quinlan* decision) found that they achieved a consensus decision, even though no formal procedures had been devised for reaching such an agreement.[145] Other ethics committees have specifically repudiated the attempt to achieve a consensus.[146] The appropriate form of decision may vary with the issue being considered, the function of the ethics committee, and the nature of the larger institution. There is little reason to think that a single opinion based on a majority vote would always be appropriate, although it may be for some situations, such as the decision to refer a case to court.

The issue of who can convene and attend meetings must be resolved. The Commission's study discovered that in all committees, the responsible physician could request a meeting, while in slightly more than half the patient's family was permitted to make such a request.[147] Should all members of ethics committees be able to request a meeting? One committee decided that its members could not do this, in order to avoid the accusation that the group was meddling without authority.[148] If ethics committees are to serve in a review capacity, however, it may be desirable for members to have the authority to request a meeting. There may be some categories of life support cases that should always be reviewed. For example, the Commission proposes that virtually all such decisions for seriously ill newborns be reviewed.[149] Certain decisions for persons who have no natural surrogate might be another category. Concerning attendance, the Commission's study revealed that although all the existing ethics committees permitted the responsible physician to attend their meetings, other people, such as the patient's clergy and family, were far less frequently allowed to attend.[150]

The way to publicize the committee's existence to health care professionals and patients needs to be considered. In one hospital with a well-established and active ethics committee, only 9 of 120 outpatients surveyed knew of its existence, though 76% answered that such committees were needed.[151] Clearly, for a committee to be used when needed, all involved must know both of its existence and of the expectation that it will be called upon.

The use of ethics committees raises serious privacy problems. Patients (and their families) could be unhappy about

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[145] Esqueda, *supra* note 121, at 26, 27.
[146] Freedman, *supra* note 118, at 21.
[147] Table F4, p. 452 *infra*.
[148] Freedman, *supra* note 118, at 21.
[149] *See* p. 227 *infra*.
[150] Table F4, p. 452 *infra*.
[151] Letter from Stuart Youngner to Joanne Lynn (Jan. 25, 1983).

their medical records being conveyed to ethics committee members without their consent, especially when neither the patients nor their families may themselves be entitled to request or attend a meeting of the committee. Privacy considerations also apply to the keeping of records of committee deliberations and to the use that may be made of any cases discussed. In order to have some basis on which to assess the efficacy of a committee's deliberations over time, some record of the deliberations may be needed. One committee in fact prepares a written summary of its meetings.[152] Yet if records are kept, their use must be restricted. The well-established, active committee just mentioned, for example, prohibits the use as teaching material of specific cases discussed by the committee.[153] Questions regarding the use of committee records as evidence in litigation must also be resolved.

Another legal issue of some concern is the liability of surrogates and practitioners, members of ethics committees, and the institutions in which the committees function. Questions have been raised about the distorting effects of entirely freeing from criminal and civil liability those who must make decisions on behalf of incapacitated persons.[154] Although they should be protected while acting with due care and diligence, primary decisionmakers and those who review their decisions should not be entirely relieved of legal responsibility. The appropriate standard of liability should be determined not simply by worries about ensuring that individuals will serve as members of ethics committees, but also by a concern that their deliberations not be unduly circumscribed by concerns about prosecution.[155] Perhaps a "good faith" standard and exclusion from criminal conspiracy liability would suffice.

Finally, if a major advantage of institutional ethics committees is that they will provide an alternative to court review in most cases, careful attention must be paid to the acceptability of the committees within existing legal structures. In a few states, the courts have held that only the judiciary has the legitimate authority and disinterested stance to make decisions for incapacitated patients.[156] If this rule were to prevail, ethics committees could become at best a helpful step in the review process leading to judicial judgment, and at worst simply another source of delay.

The Commission believes that ethics committees and other institutional responses can be more rapid and sensitive than

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[152] Freedman, *supra* note 118, at 21.

[153] *Id.* at 22.

[154] Annas, *supra* note 139, at 30-31.

[155] A first model statute to regulate the authority and responsibilities of hospital ethics committees has been drafted; *see* Appendix F, pp. 439-42 *infra*.

[156] See notes 109 and 111 *supra*.

judicial review: they are closer to the treatment setting, their deliberations are informal and typically private (and are usually regarded by their participants as falling within the general rules of medical confidentiality), and they are able to reconvene easily or delegate decisions to a separate group of members. Yet before recommending that this approach be more widely adopted—much less that it become a uniform requirement imposed by the Federal government or by hospital accreditation bodies—the Commission believes that the questions raised here about the advantages and disadvantages of such committees must be answered.

The experience with Institutional Review Boards (IRBs) is instructive. Over the past 15 years, IRBs have been developed as a way to review in advance research that exposes human subjects to risk for the benefit of science and society.[157] Formerly, ethical considerations involved in selecting and securing the voluntary informed consent of human subjects had been left largely to the conscience of individual physician-investigators, guided by the norms of the profession and by the prospect of liability or discipline for inappropriate conduct. Although initially somewhat controversial, IRBs are now generally accepted in the biomedical community and are usually thought to be effective in protecting human subjects, in improving public confidence in the research process, and in provoking self-scrutiny on the part of biomedical investigators.[158]

Nevertheless, as the Commission noted in its Second Biennial Report,[159] which deals with human research regulations, surprisingly little is known about the actual operations of such committees, beyond anecdotal accounts and several studies conducted nearly a decade ago. When IRBs were being instituted as a result of Federal guidelines and regulations, no studies were done of their relative efficacy compared with

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[157] *See, e.g.*, John A. Robertson, *The Law of Institutional Review Boards*, 20 U.C.L.A. L. Rev. 485 (1979); Robert J. Levine, Ethics and Regulation of Clinical Research, Urban & Schwarzenberg, Baltimore, Md. (1981).

[158] "And you and I have colleagues that did research that you, I, and they would call outrageous in the 1950s, who now say, God, how did I ever do that? You know how I did stuff like that? I just never had to talk to anybody about it. And that was the missing ingredient." Testimony of Dr. Norman Fost, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 148.

[159] President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research, Implementing Human Research Regulations U.S. Government Printing Office, Washington (1983). *See also* National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research, Report and Recommendations: Institutional Review Boards, U.S. Government Printing Office, Washington (1978).

groups of different composition or with entirely different mechanisms for prospective or retrospective review. Without questioning the general sense that IRBs have been helpful, the Commission believes that any increase in the use of institutional ethics committees to safeguard the interests of incompetent patients should be accompanied by more rigorous study than IRBs initially received.

Whatever the precise nature of the policies formulated, the Commission believes that institutions should recognize and evaluate the problems posed by the need to make decisions for incapacitated persons and should ensure that the decisions made promote their well-being. To provide a basis for evaluating the different forms of decisionmaking, it is especially important that institutions be explicit about the practices they adopt, and that they report their successes and failures.[160]

[160] This need to report on practices is especially important in light of a concern common among ethics committee members that they are unaware of the existence of other such committees. Communication among committees and in the literature has an important role to play in improving the efficacy of such committees. Esqueda, *supra* note 121, at 26, 30.

Patients with Permanent Loss of Consciousness

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The general public probably first became aware of the issues addressed in this chapter following the tragedy that began for a New Jersey family on April 15, 1975. On that day, Karen Ann, the 21-year-old daughter of Joseph and Julia Quinlan, lapsed into a coma from which she has never recovered.[1] In the years since, as her situation ceased being solely a private, family concern and—because of legal proceedings[2]—became front-page news, people across the country have confronted such difficult questions as:

- what is the relationship of permanent unconsciousness to life and death?

[1] Sometime after she ceased breathing for unknown reasons, Karen Quinlan was brought, unconscious, to a hospital emergency room. After her condition stabilized, feeding required a nasogastric tube and breathing required a respirator. She never experienced irreversible cessation of all brain functions (that is, death) but rather retained function of the brain stem and was diagnosed as being in a "persistent vegetative state," a condition that has not changed. Joseph Quinlan and Julia Quinlan, with Phyllis Battelle, KAREN ANN: THE QUINLANS TELL THEIR STORY, Doubleday & Co., Garden City, N.Y. (1977).

[2] Karen Quinlan's father sought court appointment as guardian of her person for the express purpose of authorizing the removal of her respirator, whether or not she died as a consequence. He was opposed not only by Karen's physicians but by the local prosecutor and the state attorney general. The New Jersey Supreme Court, however, granted his request. Her physicians gradually discontinued the respirator during May of 1976 and she was able to breathe on her own; at this writing she is alive, cared for in a New Jersey nursing home. *In re* Quinlan, 70 N.J. 10, 355 A. 2d 647, *cert. denied* 429 U.S. 922, (1976); IN THE MATTER OF KAREN QUINLAN (2 vol.), Univ. Publications of America, Frederick, Md. (1977).

- how reliable is the medical prognosis of permanence of unconsciousness?
- what life-extending care should be considered unnecessary in the context of patients with little or no chance of regaining cognitive functions?

Uncertainties regarding the care of long-term unconscious patients have been raised with increasing frequency,[3] though the number of such patients whose care has become the subject of judicial scrutiny still represents only a fraction of the total number of permanently unconscious patients.

The Commission's involvement with the issues raised by this group of patients began with its Congressionally mandated study of the "definition" of death.[4] In an empirical investigation conducted as part of that study, the Commission found that although two-thirds of the patients who are supported by an artificial respirator during a coma of at least six hours

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[3] *See, e.g.*, Lawrence K. Altman, *Princess Death: U.S. Physicians Raise Questions*, N.Y. TIMES, Sept. 21, 1982, at C-1; Glenn Collins, *When Life is a Matter for Debate*, N.Y. TIMES, Aug. 16, 1982, at B-12.

In addition to the well-known *Quinlan* case, there have been several other court reviews of the case of comatose patients. Dockery v. Dockery, 559 S.W. 2d 952 (Tenn. App. 1977) (appeal of chancery court order, which appointed husband as guardian for purposes of authorizing removal of respirator from comatose wife, mooted by wife's death); *In re* Piotrowicz, No. 1948 (Essex Cty., Mass. Probate Ct., Dec. 23, 1977) (husband appointed guardian of 56-year-old comatose wife for purposes of authorizing withdrawal of respirator); *In re* Nichols, No. A99511, Orange Cty. Calif. Super. Ct. (March 21, 1979) discussed in Note, *Comatose Conservatee—Restrictions of Legal Capacity—Substance or Procedure?*, 7 WASH ST. U. L. REV. 205 (1980); Leach v. Akron General Medical Center, 426 N.E.2d 809 (Ohio Com. Pl. 1980) (family sought directive to disconnect life support); *In re* Storar 52 N.Y.2d 363, 420 N.E.2d 64 (1981), *modifying* Eichner v. Dillon, 426 N.Y.S.2d 527 (App. Div. 1980) (in which a comatose Catholic priest, Brother Joseph Fox, was allowed to have treatment stopped because he had given strong advance directives); Severns v. Wilmington Medical Center, Inc., 421 A.2d 1334 (Del. 1980) (comatose woman with substantial advance deliberation allowed to stop all treatment); *In re* Lydia Hall Hospital, No. 23730182 (Special Term, Part II, Sup. Ct., Nassau County, N.Y., Oct. 22, 1982) (Peter Cinque, while competent, asked to cease dialysis and then became comatose after a resuscitation effort and court ordered discontinuation of treatment on family request); *In re* Cruse, No. J914419 and *In re* Guardianship of Cruse No. P645318 (Sup. Ct., Los Angeles, Cal., Feb. 15, 1979) (3-year-old child in coma, life-support discontinuance authorized); *In re* Young, No. A100863 (Sup. Ct., Orange County, Cal., Sept. 11, 1979) (removal of respirator allowed for comatose automobile accident victim).

[4] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, DEFINING DEATH, U.S. Government Printing Office, Washington (1981).

duration are dead within a month, about 6% remained indefinitely in a "persistent vegetative state."[5] The Commission was especially interested in this group for two reasons. First, for many years the leading set of clinical criteria for the determination of "brain death" were those published in 1968 under the title "A Definition of Irreversible Coma."[6] Using this term as synonymous with death unfortunately served to perpetuate a confusion in the medical field between the state of being permanently unconscious, as are patients in a persistent vegetative state, and that of being dead.[7] Second, and more importantly, once it is acknowledged that permanently unconscious patients are not dead, difficult questions are raised about the type and extent of care that should be provided for them.

Since permanently unconscious patients raise issues at least as difficult as those considered in *Defining Death*, the Commission resolved to give this group special attention in the present study. Two major issues are presented: Who are these patients exactly? And what issues arise during their care that are different from those of other incompetent patients? The first section of this chapter addresses the theoretical concerns in making a diagnosis of permanent loss of consciousness and identifies the major groups of patients in this state, though the Commission leaves to the appropriate biomedical experts the task of providing working guidelines for making the medical diagnosis. After establishing that some patients' unconsciousness can be reliably predicted to be permanent, the chapter attempts to clarify what should be considered permissible care of these patients. The second section evaluates the considerations that would justify continued treatment of these patients. Next, current treatment practices are described and the Commission's analysis is used to distinguish unacceptable practices from desirable ones. The final section presents the Commission's recommendations for decisionmaking processes that encourage both justifiable assignment of authority to decide and ethically defensible decisions.

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[5] About 12%, typically those whose coma was due to drug intoxication, made a good to moderate recovery, and about an equal number were left with severe disability, though they regained consciousness. *Id.* at 94.

[6] Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 J.A.M.A. 377 (1968).

[7] *See* Julius Korein, *Terminology, Definitions and Usage*, 315 ANNALS N. Y. ACAD. SCI. 6 (1978); testimonies of Dr. Lawrence Pitts, Dr. Robert Kaiser, and Mr. Leslie Rothenberg, transcript of 12th meeting of the President's Commission (Sept. 12, 1981) at 348-65; testimony of Dr. David Levy, transcript of 15th meeting of the President's Commission (Dec. 12, 1981) at 275-82.

Identifying Patients

Unconsciousness. No one can ever have more than inferential evidence of consciousness in another person. A detailed analysis of the nature of consciousness is not needed, however, when considering the class of patients in whom *all* possible components of mental life are absent—all thought, feeling, sensation, desire, emotion, and awareness of self or environment.[8] Retaining even a slight ability to experience the environment (such as from an ordinary dose of sedative drugs, severe retardation, or the destruction of most of the cerebral cortex) is different from having no such ability, and the discussion in this chapter is limited to the latter group of patients.

Most of what makes someone a distinctive individual is lost when the person is unconscious,[9] especially if he or she will always remain so. Personality, memory, purposive action,

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[8] A determination of unconsciousness will therefore generally be based upon evidence that the person lacks any responsiveness to the internal or external environment (excepting unmodulated reflex responses), does not engage in purposive action, and manifests no other signs of mental activity.

[9] Two other terms could have been used: "coma" and "vegetative state." But "coma" has often been used imprecisely and both terms might connote only a subset of the relevant group. Sometimes coma is graded to reflect all possible degrees of impaired consciousness. *See, e.g.*, Graham Teasdale and Bryan Jennett, *Assessment of Coma and Impaired Consciousness—A Practical Scale*, 1 LANCET 81 (1974); Bruce D. Snyder *et al., Neurologic Prognosis after Cardiopulmonary Arrest: II. Level of Consciousness*, 30 NEUROLOGY 52 (1980). Others have insisted upon a more restrictive definition that includes absence of eye opening. "Coma is complete unresponsiveness with eyes closed." Fred Plum, *Consciousness and Its Disturbances: Introduction*, in Paul B. Beeson, Walsh McDermott, and James B. Wyngaarden, eds., CECIL TEXTBOOK OF MEDICINE, W.B. Saunders Co., Philadelphia (15th ed. 1979) at 640. The first usage is overly inclusive for the present discussion, as it includes responsive and sentient individuals; the second definition is overly restrictive as it excludes unconscious patients whose eyes open, like those in a "vegetative state," a large subgroup of patients with permanent unconsciousness.

The term "vegetative state" (or, more anatomically, "apallic syndrome") denotes unconsciousness with persistent brain-stem functions that maintain subsistence functions and often wakefulness. It includes patients with the appearance of wakefulness but conversely excludes those who are more deeply comatose with closed eyes. *See* David H. Ingvar *et al., Survival after Severe Cerebral Anoxia with Destruction of the Cerebral Cortex: The Apallic Syndrome*, 35 ANNALS N.Y. ACAD. SCI. 184 (1978). The term needed for the discussion in this Report was selected to include deep coma and vegetative state but to exclude patients with partial impairments of consciousness. "Permanent loss of consciousness" accomplishes this.

social interaction, sentience, thought, and even emotional states are gone.[10] Only vegetative functions and reflexes persist. If food is supplied, the digestive system functions and uncontrolled evacuation occurs; the kidneys produce urine; the heart, lungs, and blood vessels continue to move air and blood; and nutrients are distributed in the body.

Exceedingly careful neurologic examination is essential in order for a diagnosis of complete unconsciousness to be made. Application of noxious stimuli to the nerve endings of an unconscious patient leads to simple, unregulated reflex responses at both the spinal and the brain stem levels. Reflexes may allow some eye movement, grimacing, swallowing, and pupillary adjustment to light. If the reticular activating system in the brain stem is intact, the eyes can open and close in regular daily cycles. The reflex activity can be unsettling to family and other observers, but the components of behavior that produce this appearance are "accompanied by an apparent total lack of cognitive function."[11] In order to have awareness, a person must have an integrated functioning of the brain stem's activating system with the higher "thinking" functions from the thalamus and cerebral hemispheres.[12] Many patients whose brain dysfunctions cause unconsciousness nevertheless have a fairly intact brain stem and, if provided extensive nursing care, are able to remain alive without respirator support for many years.

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[10] Some hold that such a patient ought not to be considered a "person." *See* Joseph Fletcher, *Indicators of Humanhood*, 2 HASTINGS CTR. REP. 1, 3 (Nov. 1972); Lawrence C. Becker, *Human Being: The Boundaries of the Concept*, 4 PHIL. & PUB. AFFAIRS 334 (Summer 1975); John Lachs, *Humane Treatment and the Treatment of Humans*, 294 NEW ENG. J. MED. 838 (1976). Rather than attempt to define "person," the Commission has concentrated on delineating the obligations to provide care to patients who have permanently lost consciousness, since it had earlier concluded that such patients are living human beings. DEFINING DEATH, *supra* note 4, at 7, 38-41.

[11] Fred Plum and Jerome B. Posner, THE DIAGNOSIS OF STUPOR AND COMA, F.A. Davis Co., Philadelphia (3rd ed. 1980) at 6.

[12] Medical science has been unable to detect or postulate neurologic damage to the brain that would result in a functioning cerebrum capable of consciousness but able to perform absolutely no purposeful actions. At the least, to have consciousness a person must have some functioning cerebrum connected to adequate activating structures in the midbrain. Neurological findings indicate that having that much of a functioning central nervous system entails having at least the ability to blink voluntarily or move the eyes deliberately, and usually much more. Patients with the rare neurologic syndrome termed "locked-in state" retain only the ability to control movements of the eyes or eyelids. *See, e.g.*, Martin H. Feldman, *Physiological Observations in a Chronic Case of "Locked-in Syndrome,"* 21 NEUROLOGY 459 (1971); Plum and Posner, *supra* note 11, at 6, 24.

Permanence. The other essential property of this category of patients is that their unconsciousness is permanent,[13] which means "lasting...indefinitely without change; opposed to temporary."[14] Three sources of uncertainty should be acknowledged about any judgment that a particular patient's unconscious state is permanent.

The first uncertainty affects any scientific proposition about as-yet-unobserved cases. No matter how extensive the past evidence is for an empirical generalization, it may yet be falsified by future experience. Certainty in prognosis is always a matter of degree, typically based upon the quantity and quality of the evidence from which a prediction is made.

Second, this empirical qualification is especially serious in predictions about unconsciousness because the evidence relevant to a prognosis of permanence is still quite limited. The overall number of such patients is small,[15] and most cases have

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[13] The term "permanent" could have been replaced by "persistent," "irreversible," or "judged to be permanent." "Persistent" was rejected because it can apply to situations that are not permanent. Ordinarily a situation is persistent when it lasts a long time, but not necessarily forever. However, repeated evaluations over a period of persistence is often essential to a reliable prognostication of permanence.

"Irreversible" not only conveys permanence but also focuses upon the prognostication of therapeutic possibilities, which might be a beneficial additional nuance. However, using "irreversible" to refer to this class of patients is virtually precluded by its inappropriate use in the phrase "irreversible coma" to describe neurologically dead bodies maintained on artificial circulatory and respiratory support. *See* notes 6 and 7, *supra*.

The phrase "judged to be permanent" would highlight the irreducible element of probabilistic judgment that is part of the diagnosis of permanent unconsciousness. However, since such judgment is an essential part of every scientific prognostication, it is redundant and unnecessarily awkward. *See, e.g.*, Alvan R. Feinstein, Clinical Judgment, Robert Kreiger Pub. Co., Huntington, N. Y. (1967); Mark Siegler, *Pascal's Wager and the Hanging of Crepe*, 292 New Eng. J. Med. 853 (1975).

[14] Compact Edition of the Oxford English Dictionary, Oxford University Press, New York (1971) at 710.

[15] The only prevalence survey available estimates that Japan has about 2000 permanently unconscious patients in long-term care, which, if the prevalence were the same (and if differing definitions of terms did not cause substantial error), would imply less than 5000 at any one time in the United States. S. Sato *et al., Epidemiological Survey of Vegetative State Patients in Tokuhu District in Japan*, 8 Neurologia Medico-Chirurgia (Tokyo) 141 (1978). *See also*, Peter Perl, *Silent Epidemic: Modern Medicine Saves Victims of Crash but Creates Dilemma: Coma*, Wash. Post, March 18, 1982, at A-1; William D. Kalsbeek *et al, National Head Injury and Spinal Cord Injury Survey: Major Findings*, 53 J. Neurosurg. 19 (Supp. 1980); Defining Death, *supra* note 4, at 92-95. Dr. Ake Grenvik reports between 500

not been carefully studied or adequately reported. Furthermore, the number of variables affecting prognosis (for example, the cause of unconsciousness, the patient's age and other diseases, the length of time the patient has been unconscious, and the kinds of therapy applied) is large and imperfectly understood.

Finally, any prediction that a patient will not regain consciousness before dying, regardless of the treatment undertaken, contains an implicit assumption about future medical breakthroughs. Since some such patients can be maintained alive for extended periods of time (often years rather than days, weeks, or months),[16] this assumption about treatment innovations can be a long-range one. At the moment, however, it introduces only a very small uncertainty, since the possibility of repairing the neurologic injuries that destroy consciousness is exceedingly remote.

Given these three qualifications on the meaning and basis of any judgment regarding permanence, such a judgment is always a matter of probability about whether a particular patient will remain unconscious until he or she dies despite any treatment that might be undertaken. Nevertheless, the Commission was assured that physicians with experience in this area can reliably determine that some patients' loss of consciousness is permanent.[17]

Disease Categories. Only a few fairly uncommon diseases cause permanent loss of consciousness. The pathophysiology of an unconscious state that becomes permanent entails severe disruption of the coordinated functioning of the cerebral hemispheres and the midbrain but with retention of sufficient brain-stem activity to sustain vegetative functions. Most commonly, this occurs when the cerebral hemispheres are

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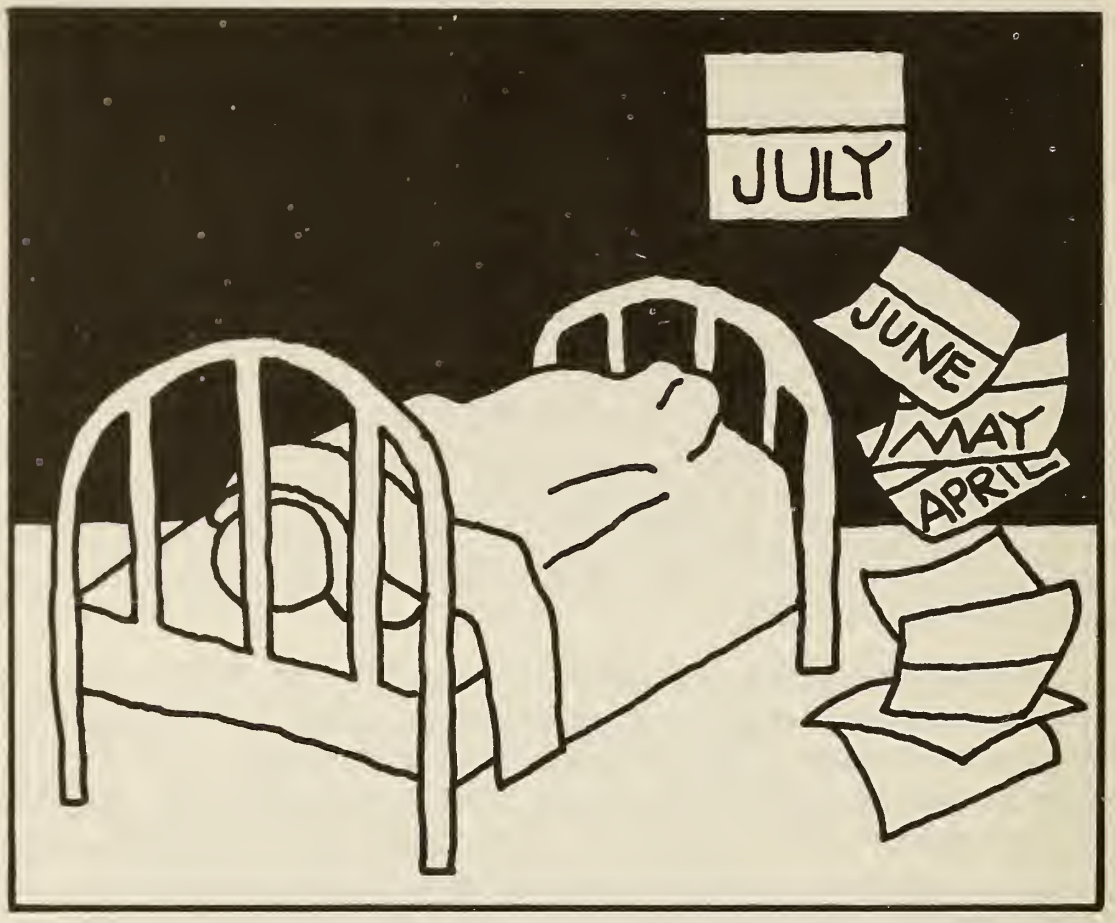
and 1000 patients at Presbyterian-University Hospital in Pittsburgh have had life-sustaining treatment withdrawn because of permanent loss of the important cortical layers of the brain. Letter to Joanne Lynn, Dec. 14, 1981.

[16] The longest case of coma on record is that of Elaine Esposito, who never recovered consciousness after receiving general anesthesia for surgery on August 6, 1941. She died 37 years and 111 days later. Norris McWhirter, ed., THE GUINNESS BOOK OF WORLD RECORDS, Bantam Books, New York (1981) at 42. *See also* the description of a woman injured at age 27 who neither regained consciousness nor left the hospital during the remaining 18 years of her life. Robert E. Field and Raymond J. Romanus, *A Decerebrate Patient: Eighteen Years of Care*, 151 ILL. MED. J. 121 (1977).

[17] Letter from Dr. Fred Plum, Neurologist-in-Chief, New York Hospital-Cornell Medical Center, New York, Dec. 22, 1981, *reprinted in* Appendix G, pp. 459-60 *infra*. *See also, Predicting Outcome After Severe Brain Damage* (Editorial), 1 LANCET 523 (1973); Eichner v. Dillon, 426 N.Y.S.2d 517, 527-529, *modified in, In re* Storar, 420 N.E.2d 64 (1981).



profoundly injured but the brain stem is nearly entirely spared. Diagnosis in these cases typically involves extensive physical examination, special radiographic and other imaging procedures, and circulation studies of the brain.

Although many individuals with such an injury survive only briefly, some stay alive for an indefinite period and die of some other illness, often contracted while they are unconscious. Nearly all such long-term survivors are in the diagnostic category of "persistent vegetative state" (PVS).[18] This syndrome usually arises from head injury (as from fights, gunshots, or automobile accidents), intracranial hypoxia (as from cardiac arrest, asphyxiation, or hypotensive shock), or intracranial hypoglycemia (as from insulin overdose). If a patient who is initially comatose from a head injury fails to become responsive and aware within a few weeks, the prognosis for any recovery becomes extremely remote. The absence of all responsiveness, vocalization, or purposive

[18] Bryan Jennett and Fred Plum, *The Persistent Vegetative State: A Syndrome in Search of a Name*, 1 LANCET 734 (1972); K. Higashi *et al.*, *Epidemiological Studies on Patients with a Persistent Vegetative State*, 40 J. NEUROL., NEUROSURG. & PSYCHIATRY 876 (1977); Plum and Posner, *supra* note 11, at 338-40.

action one month after the trauma makes a lack of recovery virtually certain, despite vigorous therapy.[19] The incidence of head injuries leading to permanent coma or vegetative state is unclear, as there is no central registry, but preliminary evidence seems to point to at least a few cases each year at each large referral hospital.[20]

As with head injury, hypoxic and hypoglycemic damage to the brain often initially causes loss of function in areas of the brain that might recover with time and treatment. However, probably 12% of patients with nontraumatic coma develop reliably diagnosed PVS.[21] Two patients recovered consciousness after a year of PVS from hypoxia.[22] Recovery of consciousness is very unlikely, however, for patients with hypoxia who remain comatose or in PVS for more than one month.[23] Certainly, extended observation is appropriate before

[19] Testimony of Dr. Lawrence Pitts, transcript of 12th meeting of the President's Commission (Sept. 12, 1981) at 348-64; Bryan Jennett *et al., Severe Head Injuries in Three Countries*, 40 J. NEUROL., NEUROSURG., & PSYCHIATRY 291 (1977).

[20] Bryan Jennett *et al., Prognosis of Patients with Severe Head Injury*, 4 NEUROSURGERY 283 (1979); Thomas W. Langfitt, *Measuring the Outcome from Head Injuries*, 48 J. NEUROSURG. 673 (1978); DEFINING DEATH, *supra* note 4, at 89-107.

[21] *See* David Bates *et al., A Prospective Study of Nontraumatic Coma: Methods and Results in 310 Patients*, 2 ANNALS NEUROL. 211 (1977); David E. Levy *et al., Prognosis in Nontraumatic Coma*, 94 ANNALS INT. MED. 293 (1981); Higashi, *supra* note 18; DEFINING DEATH, *supra* note 4, at 92-95.

[22] In one case, cognitive abilities became normal, although the patient suffered from emotional instability and paralysis of three limbs and remained completely dependent upon others for the rest of his life. Gary A. Rosenberg, Stephen F. Johnson, and Richard P. Brenner, *Recovery of Cognition after Prolonged Vegetative State*, 2 ANN. NEUROL. 167 (August 1977). The other case has recovered only to a locked-in status, with all communication by eyeblink. Lewis Cope, *Doctors Think Mack "in vegetative state,"* MINNEAPOLIS TRIBUNE, March 20, 1980, at A-1; David Peterson, *Shooting Case Turns into Vigil*, MINNEAPOLIS TRIBUNE, March 7, 1980, at A-1; telephone interviews with Ronald Cranford, M.D., consultant neurologist on this case, Hennepin County Hospital, Minneapolis, Minn., March 8, 1982, and Dec. 2, 1982.

[23] *Outcome of Non-Traumatic Coma* (Editorial), 2 LANCET 507 (1981); J.A. Bell and H.J.F. Hodgson, *Coma after Cardiac Arrest*, 97 BRAIN 361 (1974); Fred Plum and John J. Caronna, *Can One Predict Outcome of Medical Coma?*, Outcome of Severe Damage to the Central Nervous System, CIBA Foundation Symposium #34, Elsevier-North Holland, Amsterdam, (1975) at 121; Bruce D. Snyder, Manuel Ramirez-Lassepas, and D.M. Lippert, *Neurologic Status and Prognosis after Cardiopulmonary Arrest: I. A Retrospective Study*, 27 NEUROLOGY 807 (1977); Bruce D. Snyder, *et al., Neurologic Prognosis after Cardiopulmonary Arrest: II. Level of Consciousness*, 30 NEUROLOGY 52 (1980). Jorgensen and Malchow-Moller contend that recovery of consciousness before death

making a diagnosis of permanent unconsciousness, at least for hypoxic injuries in otherwise healthy young people.[24]

In addition to those with PVS, four other groups of patients might be diagnosed to be permanently unconscious. First are those who are unresponsive after brain injury or hypoxia and who do not recover sufficient brain-stem function to stabilize in a vegetative state before dying. Most of these die within a few weeks after the brain damage. Although the number of patients in this category is uncertain, it is probably large; more than half the individuals for whom cardiac resuscitation is initially successful die without recovering consciousness, mostly in the first few days.[25]

Second, the end-stage victims of such degenerative neurologic conditions as Jakob-Creutzfeldt disease and severe Alzheimer's disease are permanently unconscious. Only in their final stages do these illnesses become so severe as to bring on complete unconsciousness, and the life span thereafter is only a few weeks or months, depending in part on the extensiveness of support given. Again, the incidence of this source of irreversible unconsciousness is unknown.

A third group of permanently unconscious patients who are in a coma rather than in persistent vegetative state are those who have intracranial mass lesions from neoplasms or vascular masses. If the lesion is correctable, some of these unconscious patients might have restoration of some con-

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can be reliably predicted from careful attention to the time course of EEG and brain stem reflex activity in the first 10 to 36 hours. E.O. Jorgensen and A. Malchow-Moller, *Natural History of Global and Critical Brain Ischaemia: Part III: Cerebral Prognostic Signs After Cardiopulmonary Resuscitation. Cerebral Recovery Course and Rate during the First Year after Global and Critical Ischaemia Monitored and Predicted by EEG and Neurological Signs*, 9 RESUSCITATION 175 (1981). Snyder *et al.* state that "Reliable predictions of survival and outcome can often be based up on LOC [level of consciousness] within 2 days after CPA [cardiopulmonary arrest]." Bruce D. Snyder *et al., Neurologic Prognosis after Cardiopulmonary Arrest: II. Level of Consciousness*, 30 NEUROLOGY 52 (1980). Evoked potentials may add to the reliability of these early prognostications. Richard Paul Greenberg and Donald Paul Becker, *Clinical Applications and Results of Evoked Potential Data in Patients with Severe Head Injury*, 26 SURG. FORUM 484 (1975).

[24] This caution might be especially appropriate in children. *See, e.g.*, "The brains of infants and young children have increased resistance to damage and may recover substantial functions even after exhibiting unresponsiveness on neurological examination for longer periods compared with adults." Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Guidelines for the Determination of Death*, 246 J.A.M.A. 2184, 2186 (1981).

[25] *See, e.g.*, Snyder, Ramirez-Lassepas, and Lippert, *supra* note 22; Bell and Hodgson, *supra* note 22; DEFINING DEATH, *supra* note 4, at 92-95.

sciousness. However those for whom there is no effective therapy will be unconscious until they die. Such states usually last only for a few days or weeks, and their frequency is unknown.

The fourth source of permanent unconsciousness is congenital hypoplasia of the central nervous system (anencephaly). Various degrees of hypoplasia and dysplasia are possible and some engender brief vegetative life without development of any mentation or cognition. Usually such conditions are apparent because of abnormalities of the cranium at birth. Sometimes the infant is fairly normal, however, and only the failure to achieve the usual developmental landmarks or the appearance of other medical complications leads to detection. Most babies whose anencephaly precludes development of any consciousness die within a few days of birth, and none survive for more than a few months. This condition afflicts one of every 850 births, for an annual incidence of 4000 in the United States.[26]

Reasons for Continued Treatment

Physicians arrive at prognoses of permanent unconsciousness only after patients have received vigorous medical attention, careful observation, and complete diagnostic studies, usually over a prolonged period. During this time when improvement is thought to be possible, it is appropriate for therapies to be intensive and aggressive, both to reverse unconsciousness and to overcome any other problems. Once it is clear that the loss of consciousness is permanent, however, the goals of continued therapy need to be examined.

The Interests of the Patient. The primary basis for medical treatment of patients is the prospect that each individual's interests (specifically, the interest in well-being) will be promoted. Thus, treatment ordinarily aims to benefit a patient through preserving life, relieving pain and suffering, protecting against disability, and returning maximally effective functioning. If a prognosis of permanent unconsciousness is correct, however, continued treatment cannot confer such benefits. Pain and suffering are absent, as are joy, satisfaction, and

[26] *See* Gayle C. Windham and Larry D. Edmonds, *Current Trends in the Incidence of Neural Tube Defects*, 70 PEDIATRICS 333 (1982); Lewis B. Holmes, *The Health Problem: Neural Tube Defects*, in National Center for Health Care Technology, MATERNAL SERUM ALPHA-FETOPROTEIN: ISSUES IN PRENATAL SCREENING AND DIAGNOSIS OF NEURAL TUBE DEFECTS, U.S. Government Printing Office, Washington (1980). The annual number of live births used to calculate incidence is from U.S. Department of Health and Human Services, *Health United States 1981*, U.S. Government Printing Office, Washington (1981).

pleasure. Disability is total and no return to an even minimal level of social or human functioning is possible.[27]

Any value to the patient from continued care and maintenance under such circumstances would seem to reside in the very small probability that the prognosis of permanence is incorrect.[28] Although therapy might appear to be in the patient's interest because it preserves the remote chance of recovery of consciousness, there are two substantial objections to providing vigorous therapy for permanently unconscious patients.

First, the few patients who have recovered consciousness after a prolonged period of unconsciousness were severely disabled.[29] The degree of permanent damage varied but commonly included inability to speak or see, permanent distortion of the limbs, and paralysis. Being returned to such a state would be regarded as of very limited benefit by most patients; it may even be considered harmful if a particular

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[27] One recent court case points out the conceptual and practical conundrums that arise in defining the interests of a person devoid of all mental life or conscious experience. The suit was brought on behalf of such a plaintiff, seeking damages for loss of enjoyment of life as a result of loss of customary activities. One of the questions for the court was whether it must be shown that the plaintiff is conscious of the fact that he has lost any enjoyment of life. The court answered that, under the disability law, conscious awareness of injuries need not be shown. Flannery v. U.S., 51 U.S.L.W 2293, 2293 (W. Va. Sup. Ct., 1982).

However, other legal questions are even more vexing:

> Someone who has died cannot be said to have "rights" in the usual sense; although a person may have a right to determine how her body is dealt with after death, even that is a troublesome concept....To be sure, Karen Quinlan was not "dead" in most of the increasingly multiple senses of that term, but the task of giving content to the notion that she had rights, in the face of the recognition that she could make no decisions about how to exercise any such rights, remains a difficult one.

Laurence H. Tribe, American Constitutional Law, Foundation Press, Mineola, N.Y. (1978) at 936, n 11.

> [28] There is a small, finite chance that she [Karen Quinlan] could recover, so keeping her alive for that reason might be a benefit to her, for it at least leaves open the possibility of recovery. This is not to say that Karen Quinlan has a very great chance of recovery, but even a small possibility suggests that it may be in her interests to continue to be alive.

John A. Robertson, *The Courts and Non-treatment Criteria*, in Cynthia B. Wong and Judith P. Swazey, eds., Dilemmas of Dying: Policies and Procedures for Decisions Not to Treat, G.K. Hall Med. Pub., Boston (1981) at 105.

[29] *See* note 22 *supra*. *See also* Martin Lasden, *Coming Out of Coma*, N.Y. Times, June 27, 1982 (Magazine) at 29.

patient would have refused treatments expected to produce this outcome. Thus, even the extremely small likelihood of "recovery" cannot be equated with returning to a normal or relatively well functioning state. Second, long-term treatment commonly imposes severe financial and emotional burdens on a patient's family, people whose welfare most patients, before they lost consciousness, placed a high value on. For both these reasons, then, continued treatment beyond a minimal level will often not serve the interests of permanently unconscious patients optimally.

The Interests of Others. The other possible sources of an interest in continued care for a permanently unconscious patient are the patient's family, health care professionals, and the public. A family possessing hope, however slim, for a patient's recovery shares that individual's interest in the continuation of treatment, namely, the possibility that the prognosis of permanent unconsciousness will prove wrong. Also, families may find personal meaning in attending to an unconscious patient, and they have a substantial interest in that patient's being treated respectfully.[30]

Health care professionals undertake specific and often explicit obligations to render care. People trust these professionals to act in patients' best interests. This expectation plays a complex and crucial part in the professionals' ability to provide care. Failure to provide some minimal level of care, even to a permanently unconscious patient, might undermine that trust and with it the health care professions' general capacity to provide effective care. Furthermore, the self-identity of physicians, nurses, and other personnel is bound in significant ways to the life-saving efforts they make; to fail to do so is felt by some to violate their professional creed.[31]

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[30] Testimony of Earl Appleby, transcript of 25th meeting of the President's Commission (Oct. 9, 1982) at 383-85.

[31] When, some six weeks after the New Jersey Supreme Court opinion authorizing the discontinuance of the respirator for Karen Quinlan, the family asked her attending physician, Dr. Robert J. Morse, why the respirator care was still being continued, Dr. Morse explained, "I have tried to explain to you, I am following medical protocol." When asked how long he would keep her on the respirator if she could not successfully be weaned, Dr. Morse replied, "For as long as it takes. Forever." Quinlan and Quinlan, *supra* note 1, at 287.

Dr. Marshall Brumer, Abe Perlmutter's physician when Perlmutter requested the Florida courts to authorize removal of his life-supporting ventilator, told the Commission: "[The Court-ordered removal of the respirator] was an execution, as the day, location, time, and mode of death were all chosen by the court." When asked how he would have treated a respirator-dependent Karen Quinlan, Dr. Brumer replied, "My opinion of the Karen Ann Quinlan case is that I would support

Consequently, health care providers may have an interest in continued treatment of these patients.[32]

Finally, society has a significant interest in protecting and promoting the high value of human life.[33] Although continued

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her with whatever technologies are available." Testimony of Dr. Marshall Brumer, transcript of 8th meeting of the President's Commission (April 19, 1981) at 16.

[32] The New Jersey Supreme Court recognized this interest, in a case involving a blood transfusion for a 23-year-old Jehovah's Witness who had been rendered incompetent and in need of blood as a result of an accident: "The medical and nursing professions are consecrated to preserving life. That is their professional creed. To them, a failure to use a simple established procedure in the circumstances of this case would be malpractice." John F. Kennedy Memorial Hospital v. Heston, 279 A.2d 670, 673 (1971).

More recently, however the Massachusetts Supreme Judicial Court denied that an independent interest of health professionals exists that would go against what patients want or will find beneficial:

> Recognition of the right to refuse necessary treatment in appropriate circumstances is consistent with existing medical mores; such a doctrine does not threaten either the integrity of the medical profession, the proper role of hospitals in caring for such patients or the State's interests in protecting the same. It is not necessary to deny a right of self-determination to a patient in order to recognize the interests of doctors, hospitals, and medical personnel in attendance on the patient. Also, if the doctrines of informed consent and right of privacy have as their foundations the right to bodily integrity and control of one's own fate, then those rights are superior to the institutional considerations.

Superintendent of Belchertown School v. Saikewicz, 370 N.E.2d 417, 426 (1977) (citation and footnote omitted).

[33] Two unusual circumstances present additional considerations for the interests of others. First, occasionally a permanently unconscious woman is pregnant. If the pregnancy can be continued to the stage of viability for the infant, the interests of the child and the family would usually provide adequate justification for vigorous life-support and therapy until delivery. *See* WASH. POST, March 2, 1982, at A-2, noting the case of a 23-year-old Oregon woman who gave birth to a 7 lb. 13 oz. child after being comatose and on life-support systems for four months. *But see* Pettit v. Chester County Hospital, No. 322, August Term 1982 (Court of Common Pleas, Chester County, Pa.); Mark Butler, *Judge Rules Comatose Woman Can Have Abortion*, PHIL. INQUIRER, Aug. 26, 1982, at A-1. *See generally* William P. Dillon *et al., Life Support and Maternal Brain Death During Pregnancy*, 248 J.A.M.A. 1089 (1982).

Second, permanently unconscious patients may be desirable subjects for research. When the research offers prospect of even distant benefit to the subject, it might be approved in the usual way. When the research is not intended to benefit the subject, it would probably be very difficult to secure legally effective consent from a surrogate. *See* President's Commission, PROTECTING HUMAN SUBJECTS,

life may be of little value to the permanently unconscious patient, the provision of care is one way of symbolizing and reinforcing the value of human life so long as any chance of recovery remains.[34] Moreover, the public may want permanently unconscious patients to receive treatment lest reduced levels of care have deleterious effects on the vigor with which other, less seriously compromised patients are treated. Furthermore the public has reason to support appropriate research on the pathophysiology and treatment of this condition so that decisions always rely upon the most complete and recent data possible.

There are, on the other hand, considerations for each of these parties—the family, health care professionals, and society—that argue against continued treatment of permanently unconscious patients. As mentioned, long-term treatment commonly imposes substantial financial burdens on a patient's family and on society[35] and often creates substantial psychological stresses for family members and providers.[36] Health

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U.S. Government Printing Office, Washington (1981) at 74-76; Task Force on Research on Senile Dementia, Vijaya Melnick, ed., *Guidelines for Research on Senile Dementia of the Alzheimer's Type*, submitted to National Institutes on Aging (Nov. 1982). Since it would be so easy to overuse these patients in research, great caution is probably appropriate before considering any weakening of the protection involved in the requirement for valid consent.

[34] At least one court has specifically denied a state interest in preserving such a patient's life: "Such a patient has no health and, in the true sense, no life for the state to protect." Eichner v. Dillon, 426 N.Y.S.2d 517, 543 (1980) *modified in, In re* Storar, 420 N.E.2d 64 (1981).

[35] In 1968 Henry Beecher estimated it would cost $25,000 to $30,000 per year for hospital care for each permanently unconscious patient. Henry K. Beecher, *Ethical Problems Created by the Hopelessly Unconscious Patient*, 278 New Eng. J. Med. 1425 (1968). While these costs are mitigated by providing care in a skilled nursing facility, inflation must also be taken into account. Even skilled nursing facilities can now cost over $25,000 per year. Telephone survey of Washington, D.C., area nursing homes (Dec. 1982).

Reported cases provide striking cost estimates. A comatose Tennessee woman who was maintained on a respirator because her death without it might lead to a murder prosecution was costing $1000 per day. David Meyers, *The California Natural Death Act: A Critical Appraisal*, 52 Cal. St. Bar J. 326 (1977). Four months of care for a comatose child cost about $40,000. *In re* Benjamin Cruse. Nos. J9 14419 and P6 45318 (Los Angeles Superior Ct., Feb. 15, 1979). The first two years of care for an adolescent with persistent vegetative state cost $280,000. Ronald E. Cranford and Harmon L. Smith, *Some Critical Distinctions between Brain Death and Persistent Vegetative State*, 6 Ethics in Sci. & Med. 199, 203 (1979). *See also* note 115, Chapter Four *supra*.

[36] The disruption of family life, together with the emotional drain on families which elect to care for these patients at home, can be very significant. Moreover, sensational but unverified

care professionals must devote scarce time and resources to treatment that is nearly certain to be futile. Any alternate useful allocation of the resources and personnel is likely to benefit other patients much more substantially.

In sum, the interests of the permanently unconscious patient in continued treatment are very limited compared with other patients. These attenuated interests in continuing treatment must be weighed against the reasons to choose nontreatment in order to arrive at sound public policy on the care of the permanently unconscious.

Managing Patients' Care

Current Practice. Scant information is available on how patients with permanent unconsciousness are most commonly managed. In testimony before the Commission, a neurosurgeon who is doing research on head trauma stated that once he is certain of this diagnosis, he orders "no new therapy."[37] Such patients often succumb to complications of their debilitated state, such as infections, which are more often lethal when antibiotics are not provided. Other cases, such as Karen Quinlan or Minneapolis police officer David Mack,[38] involved the removal of respirator support at some risk of precipitating death. In 1982 the American Medical Association's Judicial Council stated:

> Where a terminally ill patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis, all means of life support may be discontinued.[39]

Every few months there are new accounts of court cases involving unconscious patients,[40] which usually arise when a hospital or physician refuses to stop a life-sustaining therapy that family members feel should be halted. Although no data have been published on this issue, it is probably unusual for a family and physician to disagree. The family's wishes about the care of a permanently unconscious patient are probably

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reports from the lay literature regarding miraculous recovery in patients with irreversible brain damage are often unsettling to the families and a source of false hope and further emotional turmoil.

Cranford and Smith, *supra* note 35, at 206.

[37] Pitts, *supra* note 19 at 352.

[38] Sergeant David Mack is the second case in note 22 *supra*.

[39] Judicial Council of the American Medical Association, CURRENT OPINIONS, American Medical Association, Chicago (1982) at 9-10, *reprinted in* Appendix C, pp. 299-300 *infra*.

[40] *See, e.g.*, James Barron, *Diabetic Dies After L.I. Judge Stops His Life-Sustaining Care*, N. Y. TIMES, Oct. 22, 1982 at A-1; *He's in Coma so Mother Acts in Divorce Case*, PHILA. BULLETIN, Sept. 18, 1981, at A-1.

determinative in most situations when the family has a strong preference.[41] The supportive care that is usually given is probably less than fully aggressive care: permanently unconscious patients are unlikely to be admitted to an intensive care unit or to be resuscitated if cardiac arrest occurs. Most of these patients, however, are probably given such measures as basic hygiene and artificial nutrition.

In March 1981, the Los Angeles County Bar Association and the Los Angeles County Medical Association published a set of guidelines on the care of patients in irreversible coma. The two groups have tried to give the outlines of a standard of acceptable care regarding withdrawal of artificial life-sustaining equipment from such patients:

> Cardiopulmonary life-support systems may be discontinued if all of the following conditions are present:
>
> a. The medical record contains a written diagnosis of irreversible coma, confirmed by a physician who by training or experience is qualified to assist in making such decisions. The medical record must include adequate medical evidence to support the diagnosis;
>
> b. The medical record indicates that there has been no expressed intention on the part of the patient that life-support systems be initiated or maintained in such circumstances; and
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> c. The medical record indicates that the patient's family or guardian or conservator, concurs in the decision to discontinue such support.[42]

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[41] *See, e.g.*, a survey of 30 physicians in Napa, California, in October 1979, which found that 18 of the 20 physicians who responded would discontinue the respirator on a patient with permanent vegetative state if the next-of-kin agrees. If the permanently unconscious patient can breathe without artificial support, 23 of 29 physicians would stop antibiotics for pneumonia on parental request and 14 of 28 would stop nasogastric tube feedings. David Meyers, MEDICO-LEGAL IMPLICATIONS OF DEATH AND DYING, Lawyers Cooperative Publishing Co., Rochester, N.Y., (1981) at 167-168.

[42] Joint Ad Hoc Committee on Biomedical Ethics of the Los Angeles County Medical and Bar Associations, *Guidelines for Discontinuance*

This document represents an effort that is both unusual and laudable, although the actual standards are probably representative of unwritten policy in many other locations.[43]

Not only is it unclear what care is most commonly provided, but it is also not known what facilities provide care. The institution, usually a large acute-care hospital, that is caring for a patient when he or she becomes permanently unconscious is likely to continue care if the person is not expected to live more than a few weeks.[44] Patients who are expected to live longer will probably be transferred, whenever possible, from acute care hospitals to long-term care facilities such as rehabilitation hospitals and skilled nursing facilities. The type of institution providing care is likely to affect the care options that are available and encouraged.[45]

Unacceptable Practices. Some courses of care are unacceptable because they would fail to respect a patient's living body or would constitute an irresponsible stewardship of a community's resources. Errors of either sort could justifiably be proscribed by laws or regulations as well as by professional standards and policies. Errors of the first sort occur when a patient who is permanently unconscious is treated in ways that deaden the sensitivities or shock the conscience of the public, of professionals, or of the family involved, that violate the secure expectations that people reasonably have about the way they will be treated if they are ever unconscious, or that degrade the trust and confidence required for health professionals' effective performance. Direct or violent killing, abusive actions, or public viewing of a patient should certainly be considered morally reprehensible.

An irresponsible stewardship of society's resources can occur when a permanently unconscious patient is given care that precludes the treatment of others who would be helped far more than the unconscious patient. This could occur, for

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of Cardiopulmonary Life-Support Systems Under Specified Circumstances (Adopted by the Medical Assoc. March 2, 1981, and by the Bar Assoc. March 11, 1981), *reprinted in* Appendix G, pp. 461-62 *infra*.

[43] Other policies have been written. The North Carolina natural death act has provisions allowing discontinuation of life support for certain comatose patients. *See* Appendix D, pp. 357-62 *infra*. Also, the New Jersey professional associations in medicine, osteopathy, and hospital care produced guidelines to implement the *Quinlan* decision (note 2 *supra*). *See* Appendix G, pp. 463-66 *infra*. Other guidelines for decisions about the case of permanently unconscious patients have been published. In 1976, the Swiss Academy of Medical Sciences published guidelines that allow discontinuation of "special life-extending measures." *Swiss Guidelines on Care of Dying*, 7 HASTINGS CTR. REPORT 30, 31 (June 1977).

[44] *See* Matt Clark and Marsha Zabarsky, *Hope for Coma Victims*, NEWSWEEK 59 (Oct. 12, 1981).

[45] *See* pp. 106-18 *supra*.

example, were another specific patient to receive less beneficial therapy because a scarce support system is being used with a permanently unconscious patient. Whenever there is reason to believe this is happening, the patient with a remediable illness or even a chance of regaining consciousness should be put on the support system even if it precipitates the death of the permanently unconscious patient. Such an allocation upholds the highest traditions of the medical profession and should be considered to be within current standards of medical practice.

A second failure of responsible stewardship occurs when resources are expended so lavishly in the care of patients who will never regain consciousness that other important social goals are thwarted. This misallocation is usually less grave than that involving particular cases because the connection between the costs of care of the unconscious patient and any harm to others is more attenuated. For the moment, at least, total expenditures on permanently unconscious patients do not appear to be causing substantial identifiable harms to others. Nevertheless, since it is ethically acceptable to limit the provision of treatment, especially when it can at best offer a very small benefit to the patient,[46] policymakers in public and private health care payment programs may legitimately consider means of limiting, or even proscribing, these expenditures. Such limitations should not make a false distinction between the treatment of unconscious patients and other, perhaps greater, types of wasteful treatment or discriminate among unconscious patients based upon whether the reimbursement program is public or private.

Desirable Practices. Beyond these unacceptable practices, various possible treatment plans remain, ranging from aggressive measures to assure the longest possible life span to hygiene measures and dignified care for the body. As indicated, vigorous treatment to reverse or prevent all life-threatening illnesses and complications might be justified by the very small possibility of error in prognosis or by the desire to conform with a family's wishes.[47] The attenuated nature of these interests, at least compared with the obligation to benefit most other patients, argues that unlimited vigorous treatment of permanently unconscious patients may properly be discouraged, though it should not be proscribed.

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[46] *See* pp. 95-100 *supra*.

[47] The concern may also be felt that to deny therapy to these patients diagnosed permanently unconscious might lead to a reduction of vigor in treating patients with a slightly better potential for return to a sentient condition. This concern seems unpersuasive since there has been no discernible diminution in the quality of care of other patients despite several widely publicized cases in which vigorous care for permanently unconscious patients was rejected.

Less aggressive care, which would still be respectful and humane but would use fewer human and financial resources, can be an alternative plan. The kinds of treatment decisions involved relate to the support or nonsupport of vegetative functions and the complications of severe disability.

- Most patients with permanent unconsciousness cannot be sustained for long without an array of increasingly artificial feeding interventions[48]—nasogastric tubes, gastrostomy tubes, or intravenous nutrition. Since permanently unconscious patients will never be aware of nutrition, the only benefit to the patient of providing such increasingly burdensome interventions is sustaining the body to allow for a remote possibility of recovery. The sensitivities of the family and of care giving professionals ought to determine whether such interventions are made.[49]

- Unconscious patients lack control over elimination. Measures to control bowel movements and provide proper hygiene are appropriate both to preserve the dignity of the patient and to lessen the burden of the care giver, though they rarely alter a person's life span. Similarly, catheterization of the bladder to keep the patient more presentable is justifiable, though it increases the risks of infection. Surgical procedures to provide urinary drainage in instances in which simple catheterization is insufficient are more difficult to justify, however. The expense of care thereafter and the resource use in the initial procedure are substantial, while the benefit to the patient is very small. The same considerations would make it very hard to justify dialysis for a permanently unconscious patient who develops kidney failure.

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[48] Some patients retain reflex swallowing that allows oral feeding. However, at best this is very tedious for care givers and has a high risk of aspiration (with resultant pneumonia) for the patient.

[49] Where all remedial attempts have failed to bring the patient out of chronic coma, but where the patient is able to spontaneously maintain respiration and circulation, it would seem to be a matter between physician and family as to whether or not other, more mundane, care would continue....[I]f the family feels the emotional or financial drain too great and the physicians in attendance indicate no reasonable possibility of any recovery, then it can be anticipated that the courts, when presented with the petitions for appointment of a conservator with power to refuse consent to further treatment of any kind, including I.V. drip, antibiotic administration, or for that matter even maintenance in a hospital or other medical institution, can be expected to grant such requests.

Meyers, *supra*, note 41, at 171-72.

- The awkward posture and lack of motion of unconscious patients often lead to pressure sores, and skin lesions are a major complication. Treatment and prevention of these problems is standard nursing care and should be provided. After a prolonged period of paralysis, joints become fixed, and limbs and fingers become irreversibly flexed. If vigorous intervention is maintained for a few months, the patient's body can become fairly rigid in a position that is most accommodating to hygiene and skin care, which is an acceptable goal of simplifying nursing care. Deciding whether to maintain physical therapy for this purpose would depend upon the patient's projected life span and the financial and other costs of making the service available.
- Some permanently unconscious patients will have normal airways to the lungs; as part of respirator care earlier in their illness, others will have had a tracheostomy (which provides a hole through the base of the neck into the trachea). Justifying continuation of such costly and intrusive care as a respirator is exceedingly difficult.[50]
- Most of these patients periodically aspirate food or saliva into their lungs, which, combined with inactivity, often leads to pneumonia. Some physicians treat all such pneumonias with antibiotics; others leave them untreated; still others do whatever the family prefers. Though the administration of antibiotics for susceptible infections should not be so automatic a response by care givers and families that it is beyond critical scrutiny in each case, either treating or not treating pneumonia in permanently unconscious pa-

[50] Weaning a permanently unconscious patient from a respirator when death is an acceptable outcome might well be done rather differently than for patients for whom survival is of paramount importance. Ake Grenvik, *Terminal Weaning: Discontinuance of Life-Supporting Therapy in the Terminally Ill Patient* (Editorial), 11 Crit. Care Med. (forthcoming, May 1983).

Pointing out the futility of respirator care, Dennis Horan states:

> A physician is authorized under the standards of medical practice to discontinue a form of therapy which in his medical judgment is useless...If the treating physicians have determined that continued use of a respirator is useless, then they may decide to discontinue it without fear of civil or criminal liability. By useless is meant that the continued use of the therapy cannot and does not improve the prognosis for recovery.

Dennis Horan, *Euthanasia and Brain Death: Ethical and Legal Considerations*, 315 Annals N.Y. Acad. Sci. 363, 367 (1978).

tients remains morally acceptable, since at this time the additional expense of lengthened survival does not seem prohibitive.

The Decisionmaking Process

Recommending a single management scheme would be neither possible nor desirable because of the great variations in the situations of permanently unconscious patients, the nature of the institutions and persons providing care, and the desires of the families involved. First, the values and beliefs of health care professionals and the policies of the institution may place limits on the treatment options made available, even when all providers try to avoid idiosyncratic thinking or unreasonable rigidity; transfer to other care givers may not be a possibility. Second, decisions are often constrained by legal uncertainty about the effects particular courses of treatment might have for the rights and liabilities of the parties involved.[51] Third, the people who love and care about the patient should have a voice in decisions. Certain options that are morally, medically, and legally valid might be quite unacceptable to them.[52] Finally, realistic possibilities may be curtailed by the unavailability of funds and resources.

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[51] One case went to court for this reason alone:

> The attending physicians testified that in their opinion the proper course of action to follow would be to turn off the respirator and let Benjamin die. They also testified that this was the standard of medical conduct in the community and was in conformity with generally accepted medical practice. They further testified that the reason they refused to do this when the parent asked them to was because of the uncertain state of law. That is, the doctors were afraid of any resulting civil and criminal liability that might follow their actions.

In re Benjamin Cruse. Nos. J914419 and P645318, Slip op. at 5 (Los Angeles County Super. Ct. Feb. 15, 1979).

[52] Joseph and Julia Quinlan have written:

> We understand that conceivably *all* treatment of Karen Ann is extraordinary. That means the antibiotics and the food and the respirator. However, we personally have moral problems with our conscience, with regard to the food and the antibiotics. We have problems with it now, and we realize we would have more problems with it ten years from now.

Quinlan and Quinlan, *supra* note 1, at 282 (emphasis in original).

Others have, however, recognized that distinguishing feeding as more obligatory to provide for these patients is psychologically rather than ethically based. Donald G. McCarthy, *Care of Persons in the Final Stage of Terminal Illness or Irreversibly Comatose*, in Donald G. McCarthy and Albert S. Moraczewski, eds., in Moral Responsibility in Prolonging Life Decisions, Pope John Center, St. Louis, Mo. (1981) at 196.

Although a single scheme is not feasible, procedures for deciding among possible alternatives can still be endorsed. Sometimes, though infrequently, a patient will have indicated his or her preferences before losing consciousness.[53] A reasonably specific advance directive to withhold care should be honored by those responsible for a permanently unconscious patient.[54] A directive requesting continued treatment should guide those responsible but it cannot supersede their obligation to decide on management of the patient's care in light of all the circumstances, some of which may not have been foreseen by the patient when the directive was given.

When there are several treatment options that are acceptable to all interested parties and there is no advance directive from the patient, the option actually followed should generally be the one selected by the family.[55] When no alternative is acceptable to all concerned, an attempt to reach an acceptable compromise is preferable to forcing a confrontation. If substitu-

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[53] Formalization and standardization of action for patients in prolonged noncognitive states would invade the area of personal belief in a way that would harm freedom of choice. While the patient can no longer express a choice, families and physicians can. If well-documented statements from the patient, either verbal or in the form of a so-called living will, are available, the position so stated can be taken into consideration. My belief is that the end result of such reasoning together will, in most instances, provide an acceptable solution to a tragic problem. Stuart A. Schneck, *Brain Death and Prolonged States of Impaired Responsiveness*, 58 DENVER L.J. 609, 621-22 (1981).

Living wills, whether or not drafted under natural death acts, (*see* pp. 139-45 *supra*) are unlikely to apply to this situation. The permanently unconscious patient is probably not terminally ill within the meaning of the statutes, and the measures at issue are not highly intrusive and artifical, both of which are common requirements of living wills. *But see* N.C. Gen. Stat. § 90-322 (Cum. Supp. 1979) Appendix D, pp. 357-62 *infra*. It may be instructive, however, that many people feel that there is a large and growing consensus that life as a permanently unconscious patient is more horrible than death. *See* Eichner v. Dillon, 426 N.Y.S. 2d 517, *modified in, In re* Storar, 420 N.E. 2d 64 (1981).

[54] In *Eichner*, the New York State Superior Court and Court of Appeals relied on Brother Fox's statements in discussions of morals and high school teaching that he would not want to be kept alive in Karen Quinlan's situation. *See In re* Storar, 420 N.E.2d 64, 71-71 (1981).

[55] In one District of Columbia case, the court specifically declined to require formal guardianship or petition to the court. Parker v. U.S., 406 A2d 1275, 1282 (D.C. Ct. App., 1979).

tion of another provider, institution, or funding would achieve accord and is possible, such a course should be followed.[56] Where institutional ethics committees exist, their assistance should be sought since the advice of a group of concerned but disinterested people may foster understanding and agreement.[57]

If disagreement between at least two of these parties—the health care professionals, the family members, and the institution—persists after institutional review, recourse to the courts for the appointment of a guardian may be both appropriate and unavoidable.[58] Any physician involved in such a proceeding is under a strong moral obligation to assist in educating the lawyers and the court about the complexities of the situation. Courts ought to avoid deciding among treatment options, however, because explicit judicial decisions may prematurely rigidify the options available and paralyze the exercise of judgment by the parties directly involved. Rather, the court should appoint a responsible surrogate who is charged with collecting and considering the relevant information and making a decision, which might then be reported to the court.

In general, the courts have followed this course. The New Jersey Supreme Court, for example, held that the constitutional right of privacy of an unconscious patient in a situation like that of Karen Quinlan is broad enough to encompass a right to refuse the application of a mechanical respirator and that her father, as guardian, could make such a choice on her behalf.[59]

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[56] "You see, if the Quinlans had changed the doctor before they brought this case to court, it might never have come to court." Koichi Bai, *Around the Quinlan Case-Interview with Judge R. Muir*, 1 INT'L J. MED. 45, 55 (Summer 1979).

[57] *See* pp. 161-65 *supra*.

[58] It may be best to require, where any doubt or disagreement of any kind or degree exists on the part of the physician or the family as to the appropriate course of action, recourse to the courts for conservatorship powers. ...Where no such doubt or disagreement exists between family or physician and where the hopeless diagnosis has been confirmed by an independent consultant after all clinical trials have failed, it would seem unnecessary to involve the courts in any way in decisions to terminate any or all life-support systems.

Meyers, *supra* note 41, at 171-72.

[59] Unfortunately, the court went beyond appointment of the guardian and seemed occasionally to step into the role of guardian itself, giving an opinion on what Karen Ann Quinlan would want were she capable of expressing herself. The court clearly recognized that Karen Quinlan's situation differed from other cases where courts have been asked to rule on the propriety of medical treatments. The court's decision in large measure turned on to the nature of the patient's condition, the degree of invasiveness of the medical care, and the minimal hope for recovery.

A number of other cases of permanently unconscious patients have come before the courts in the seven years since the *Quinlan* decision, and guardians have uniformly been allowed to consent to withdrawal of treatment for patients whose status is comparable to hers.[60] Most of these civil cases relied

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> The nature of Karen's care and the realistic chances of her recovery are quite unlike those of the patients discussed in many of the cases where treatments were ordered. In many of those cases the medical procedure required (usually a transfusion) constituted a minimal bodily invasion and the chances of recovery and return to functioning life were very good. We think that the State's interests *contra* weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims.

In re Quinlan, 70 N.J. 10, A.2d 647, 664, *cert. denied* 429 U.S. 922 (1976).

The court was careful to note that in the future such decisions must continue to be made on the basis of reliable prognoses to ensure that there is no reasonable possibility of return to a cognitive, sapient state. For this reason it assigned the task of confirming the prognosis to an "ethics committee." *Id.* at 67. *See, New Jersey Guidelines for Health Care Facilities to Implement Procedures Concerning the Care of Comatose Non-Cognitive Patients, reprinted in* Appendix G, pp. 463-66 *infra.*

[60] *See* note 3, *supra.* In one Ohio case, the court specified certain requirements to assure the diagnosis and to notify the county coroner and prosecutor. Leach v. Akron General Medical Center, 426 N.E.2d 809 (Ohio Com. Pl. 1980).

In the case of Mary Severns, the Delaware Supreme Court, after hearing evidence that Mrs. Severns, now permanently unconscious, would not have wanted to have treatment continued and that her husband and family were in accord, ruled that treatment could be foregone. Yet the court reserved a final decision until after an evidentiary hearing before a chancery court to confirm the medical facts (which had only been presented as stipulations from unnamed physicians). Severns v. Wilmington Medical Center, Inc., 421 A. 2d 1334, 1349-50 (Del. 1980). The resulting chancery court order was quite broad, explicitly extending to authorizing refusal of resuscitation, feeding tubes, and antibiotics. *In re* Severns, No. C.M. 3722 (Ct. of Ch., New Castle County, Del., Dec. 31, 1980).

In the Brother Fox case the intermediate court ruling would have required confirmation of the prognosis of terminal illness and "irreversible, permanent or chronic vegetative coma," with "extremely remote" prospects of recovery by the majority vote of a three-member comittee. This would be followed by court review, including appointment of a guardian *ad litem* and notification of the Attorney General and appropriate District Attorney. Eichner v. Dillon, 426 N.Y.S.2d 527, 550 (1980). The court of appeals overruled the procedural aspects of the case, holding that court review is optional: "[A] mandatory procedure of successive approval by physicians, hospital personnel, relatives and the courts...should come from the Legislature." *In re* Storar, 420 N.E.2d 64, 74 (1981).

largely upon a constitutional claim of privacy on behalf of the unconscious patient against which the state had no substantial contravening interests.[61] In one criminal case, the court decided that responsibility for the permanently unconscious patient's death rested with the robber whose battery caused the unconsciousness, not the physicians who, without prior court sanction, removed a respirator.[62]

In sum, the Commission finds good decisionmaking regarding patients who have permanently lost consciousness to be possible without changes in law or other public policy. The medical profession should continue to carry its weighty obligation to establish diagnoses well and to help families understand these tragic situations. Health care institutions need to provide good policies to govern decisionmaking, including appropriate sources of consultation and advice. Family and friends of the permanently unconscious patient bear not only the protracted tragedy of their loss but also the substantial responsibility of collaborating in decisionmaking. When families can direct the care of an unconscious family member, practices and policies should encourage them to do so and should restrict the degree to which outsiders may intervene in these matters. Courts and legislatures should not encourage routine resort to the judicial system for the actual decisionmaking. Instead, courts ought to ensure that appropriate surrogates are designated and that surrogates are allowed an appropriate range of discretion.

[61] *But see, In re* Storar, 420 N.E.2d 64 (1981).
[62] Parker v. U.S., 406 A.2d 1275 (D.C. Ct. App., 1979).

Seriously Ill Newborns

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Origin and Scope of the Issue

New Medical Capabilities. Remarkable advances in neonatal care now make it possible to sustain the lives of many newborn infants who only one or two decades ago would have died in the first days or weeks after birth. Between 1970 and 1980, the death rate in the first 28 days of life (the neonatal period) was almost halved, the greatest proportional decrease in any decade since national birth statistics were first gathered in 1915.[1] Improvement among the smallest infants—those at greatest risk of death and illness—has been especially dramatic: for newborns weighing 1000-1500 grams, the mortality rate has dropped from 50% to 20% since 1961; fully half the live-born infants weighing less than 1000 grams (2.2 pounds) now survive, compared with less than 10% just 20 years ago.[2] And

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[1] Between 1970 and 1980 neonatal mortality in the U.S. declined by 24%; in comparison, the rate dropped by only 57% in the four decades between 1930 and 1970. Myron E. Wegman, *Annual Summary of Vital Statistics—1980*, 68 PEDIATRICS 755, 759 (1981). Most of the decline is attributed to improved survival rates at specific birth weights, rather than to a change in the proportion of high-risk infants born. Kwang-Sun Lee *et al., Neonatal Mortality; An Analysis of the Recent Improvement in the United States*, 70 AM. J. PUB. HEALTH 15 (1980). *See also* pp. 199-201 *infra*.

[2] Peter P. Budetti and Peggy McManus, *Assessing the Effectiveness of Neonatal Intensive Care*, 20 MED. CARE 1027 (1982). The weight of newborns is frequently reported in grams; one pound is equivalent to 454 grams. The median birthweight in the United States in 1978 was 3350 grams (7 lbs., 6 oz.). Samuel S. Kessel, Judith P. Rooks and Irving M. Kushner, *A Child's Beginning*, in Select Panel for the Promotion of Child Health, 4 BETTER HEALTH FOR OUR CHILDREN: A NATIONAL STRATEGY, Dept. of Health and Human Services, U.S. Government Printing Office, Washington (1981) at 212.

marked improvements have also been reported in the survival rate of infants with certain congenital defects.[3]

Not all seriously ill newborns fare well, however. Some infants with low birth weight or severe defects cannot survive for long, despite the most aggressive efforts to save them; others suffer severe impairments either as a component of their conditions or as a result of treatments. Thus medicine's increased ability to forestall death in seriously ill newborns has magnified the already difficult task of physicians and parents who must attempt to assess which infants will benefit from various medical interventions, and which will not. Not only does this test the limits of medical certainty in diagnosis and prognosis, it also raises profound ethical issues.

Debates about the ethics of foregoing life-sustaining treatment for newborns began to appear in professional journals in the early 1970s.[4] Ethicists, lawyers, and parents joined in the dialogue.[5] More recently, some of the controversies have been front-page news in the popular press.[6] Attention is often focused on two situations—a mentally retarded baby who requires life-saving surgery to correct a lethal physical defect,[7] and an infant with spina bifida who is expected to suffer some degree of physical and/or mental impairment even

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[3] *See, e.g.*, Kevin Turley, Constantine Mavroudis, and Paul A. Ebert, *Repair of Congenital Cardiac Lesions During the First Week of Life*, 66 CIRCULATION 214 (Suppl. I 1982); Eduardo Arciniegas *et al., Results of the Mustard Operation for Dexto-transposition of the Great Arteries*, 81 J. THORAC. CARDIOVASC. SURG. 580 (1981); Ronald D. Greenwood and Alexander S. Nadau, *The Clinical Course of Cardiac Disease in Down's Syndrome*, 58 PEDIATRICS 893 (1976).

[4] *See e.g.*, Raymond S. Duff and A.G.M. Campbell, *Moral and Ethical Dilemmas in the Special-Care Nursery*, 289 NEW ENG. J. MED. 890 (1973).

[5] *See e.g.*, Richard A. McCormick, *To Save or Let Die*, 229 J.A.M.A. 172 (1974); James M. Gustafson, *Mongolism, Parental Desires, and the Right to Life*, 292 PERSPECTIVES IN BIO. AND MED. 529 (Summer 1973); John A. Robertson, *Involuntary Euthanasia of Defective Newborns: A Legal Analysis*, 27 STAN. L. REV. 213 (1975); Albert R. Jonsen *et al., Critical Issues in Newborn Intensive Care: A Conference Report and Policy Proposal*, 55 PEDIATRICS 756 (1975); John J. Paris, *Terminating Treatment for Newborns: A Theological Perspective*, 10 L., MED. AND HEALTH CARE 120 (1982); Paul Bridge and Marlys Bridge, *The Brief Life and Death of Christopher Bridge*, 11 HASTINGS CTR. REP. 17 (Dec. 1981).

[6] *See, e.g.*, Matt Clark, Mariana Gasnell, and Dan Shapiro, *When Doctors Play God*, NEWSWEEK 48 (Aug. 31, 1981); W. Stewart Pinkerton, *Practice of Neglecting Badly Deformed Babies Stirs Troubled Debate*, WALL ST. J., July 21, 1982, at A-1; Walter Sullivan, *Life or Death Choices on Birth Defects*, N. Y. TIMES, June 19, 1981, at B-7.

[7] Perhaps the most well known of these cases is one that occurred at Johns Hopkins Hospital, where a newborn Down syndrome baby with surgically correctable duodenal atresia was left untreated and unfed; he died 15 days later. Gustafson, *supra* note 5; André Hellegers,

if operated upon immediately but who will suffer more severe impairment or die if surgery is withheld or postponed.[8] Yet actual life-and-death decisions in neonatal intensive care units (NICUs) encompass a much wider range of medical and social circumstances. In fact, these two situations account for only a small fraction of the difficult cases in decisionmaking about seriously ill newborns.[9]

In this chapter the Commission attempts to dispel the confusion that arises about the treatment of seriously ill newborns and to suggest both the range of ethically and legally acceptable decisions and who should make them. As with the other subjects in this Report, the discussion is not intended as a prescription for the outcome regarding particular decisions that must be made in the case of individual newborns; rather, it provides a framework for those—including policymakers in health care institutions and in the legal system—who are responsible for the decisionmaking process.

The Infant at Risk. Decisions about whether life-sustaining treatment is warranted for newborns arise most frequently in two general categories: infants of low birth weight and infants with life-threatening congenital abnormalities.

Low birth weight infants. Birth weight is a very strong predictor of illness and death in the neonatal period; in general, the lower the birth weight, the higher the mortality rate.[10]

Problems in Bioethics: The Johns Hopkins Case, 8 OBSTET. & GYNECOL. NEWS 40 (June 15, 1974); *Who Should Survive?* (film), produced by Joseph P. Kennedy, Jr., Foundation, Washington, D.C.

[8] Robert Reid, MY CHILDREN, MY CHILDREN: THE WORLDWIDE BATTLE AGAINST A MAJOR CRIPPLER OF CHILDREN, Harcourt Brace Jovanovich, New York (1977); Charles A. Swinyard, ed., DECISION MAKING AND THE DEFECTIVE NEWBORN, Charles C. Thomas, Springfield, Ill. (1978).

[9] The law and ethics relative to the care of newborns are unexplored territory....The problem with ethics and law in neonatology is that lawyers and philosophers have been looking at the peaks and have very little awareness of the crevices into which one can easily fall....The legal and philosophical discussions relative to neonatology are almost exclusively devoted to these two kinds of cases [Down syndrome and spina bifida]....Because there is no mention of the prominent problem, the legal analysis of neonatology misses the point. The dominant problem in the newborn nursery is prematurity.

Albert R. Jonsen, *Ethics, Law, and the Treatment of Seriously Ill Newborns*, in A. Edward Doudera and J. Douglas Peters, eds., LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS, AUPHA Press, Ann Arbor, Mich. (1982) at 236-37.

[10] Lula O. Lubchenco, THE HIGH RISK INFANT, W. B. Saunders Co., Philadelphia (1976) at 100; K. Lee, *The Very Low Birthweight: Principal Predictor of Neonatal Mortality in Industrialized Popula-*

About 230,000 infants born in the United States each year—7% of all live births—weigh 2500 grams or less, which is classified as low birth weight (LBW).[11] One study of LBW infants born at several major medical centers between 1974 and 1976 found that these small newborns were 40 times more likely than infants of normal weight to die in the neonatal period and five times more likely to die between one month and one year of age.[12] Mortality among LBW infants ranges from about 10% for those weighing 2000-2500 grams to nearly 100% for those under 750 grams. Very low birth weight infants—those who weigh less than 1500 grams—face an especially high risk of death; although they constitute only 1% of all newborns, they account for almost half of all infant deaths.[13] LBW infants are also at increased risk for serious congenital defects and impairments.[14]

Most LBW infants are premature, although some are small despite a normal gestation period. Within each LBW category, the prognosis improves with increased gestational age.[15] The most common complication of prematurity is hyaline membrane disease, a consequence of immature lung development, which is associated with 50-70% of deaths among premature infants.[16] Affected infants must be placed on mechanical ventilators to counteract the insufficient oxygen supply associated with this condition; like the disorder, this treatment can cause substantial morbidity and mortality.[17]

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tions, 97 J. PEDIATRICS 759 (1980); Lasalle D. Leffall, Jr., and Joan Maxwell, *Reducing Infant Mortality by Preventing Premature Births*, WASH. POST, Dec. 5, 1982, at C-8.

[11] Office of Technology Assessment, U.S. Congress, THE COSTS AND EFFECTIVENESS OF NEONATAL INTENSIVE CARE (Case Study #10), U.S. Government Printing Office, Washington (1981) at 11 (hereinafter cited as COSTS OF NEONATAL CARE).

[12] Sam Shapiro *et al., Relevance of Correlates of Infant Deaths for Significant Morbidity at 1 Year of Age*, 136 AM. J. OBSTET. GYNECOL. 363 (1980).

[13] COST OF NEONATAL CARE, *supra* note 11, at 11.

[14] Shapiro, *supra* note 12.

[15] Lubchenco, *supra* note 10, at 103-04.

[16] Gordon B. Avery, ed., NEONATOLOGY, J.B. Lippincott Co., Philadelphia (2nd ed. 1981) at 376.

[17] The respiratory distress syndrome (RDS) caused by hyaline membrane disease causes such complications as: respiratory failure; brief episodes without breathing (apnea); pulmonary hemorrhage; and cerebral (intraventricular) bleeding. These are serious—sometimes life-threatening—conditions. Serious intraventricular hemorrhage, for example, usually results in permanent brain damage. In addition, the mechanical ventilation often necessary to treat infants with RDS can cause morbidity. Some infants will require long-term tracheostomy, in which a tube is inserted in the neck to create an adequate airway. These infants cannot make sounds and require continuous special nursing care. Therapeutic doses of oxygen used to treat RDS can also

Feeding also presents special problems for these tiny newborns. Not only is the gastrointestinal tract unable to absorb certain foodstuffs yet, but these infants often lack the sucking and swallowing reflexes necessary for oral feeding. The amount of feeding through intravenous lines is limited both by the number of potential sites and the capacity of the immature kidneys to handle the added volume. Excess fluid intake can severely compromise an overworked heart, while an insufficent amount of fluid limits growth and denies these infants such essential nutrients as calcium. Having too little calcium can retard bone growth and increase the likelihood of bone fractures. Extremely premature infants are also very susceptible to infections (from an immature immune system), internal hemorrhage (from a deficiency of coagulation factors), anemia, and a host of other disorders.

Low birth weight is associated with several maternal risk factors. Women who have LBW infants are more likely than other mothers to be poor, nonwhite, single, poorly educated, or under 18 or over 35.[18] Inadequate prenatal health care is also strongly associated with low birth weight and infant mortality.[19]

Infants with congenital abnormalities. About 4% of the approximately 3.3 million infants born in this country each year have one or more readily detectable congenital abnormalities.[20] These infants are often born at term, rather than

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lead to retrolental fibroplasia, a cause of blindness. And the mechanical ventilation can cause permanent and sometimes progressive lung damage.

[18] *See* Victor Eisner *et al., The Risk of Low Birthweight*, 69 Am. J. Pub. Health 887 (1979); Better Health for Our Children: A National Strategy *supra* note 2, at 212.

[19] Eisner, *supra* note 18; D.M. Kessner *et al., Infant Death: An Analysis by Maternal Risk and Health Care* 1 Contrasts in Health Status, Institute of Medicine, Washington (1973); A.B. Dott and A.T. Fort, *The Effect of Maternal Demographic Factors on Infant Mortality Rates: Summary of the Findings of the Louisiana Infant Mortality Study. Part I.*, 123 Am. J. Obstet. Gynecol., 847 (1975). In 1977 about one-fourth of all mothers did not receive prenatal care during the first trimester, a critical period in the development of the fetus. Moreover, those who do not receive prenatal care tend to be the women who otherwise are at the greatest risk of having a low birth weight infant. Better Health for Our Children, *supra* note 2. A combination of factors, including availability of physicians, financing, and education, contribute to high-risk mothers not receiving the care that could prevent premature births. The Commission's Report, Securing Access to Health Care, U.S. Government Printing Office, Washington (1983), explores these issues, at 60-62, 78.

[20] This term refers to morphologic abnormalities of internal or external organs arising before birth that have actual or potential clinical significance. James B. Wyngaarden and Lloyd H. Smith, Jr., Cecil Textbook of Medicine, W.B. Saunders Co., Philadelphia (1982) at 22.

prematurely. These abnormalities have been traced to inheritance of defective genes (as in phenylketonuria or Marfan syndrome), chromosomal abnormalities (as in Down Syndrome), and environmental factors, including *in utero* viral infection or chemical exposure (one well-known instance being children born with limb abnormalities because their mothers had taken thalidomide). Although many causes of birth defects have been identified, the majority of congenital abnormalities are of unknown etiology and probably result from a complex interaction of genetic and environmental factors.[21]

Two types of congenital abnormalities have been especially prominent in discussions of the ethics of neonatal care: neural tube defects (NTDs), and permanent handicaps combined with surgically correctable, life-threatening lesions. Defects involving the neural tube, which is the embryonic precursor of the brain and spinal cord, are among the most common serious birth defects of unknown etiology, affecting approximately two of every 1000 babies born in the United States.[22] One type of NTD is anencephaly, a condition in which the brain is entirely or substantially absent. Anencephalic infants usually die within a few hours or days.[23] Another type of NTD, meningomyelocele (spina bifida) involves abnormal development of the brain or spinal cord. Spina bifida causes physical and/or mental impairments that range widely in severity and frequently involve many organ systems. Vigorous surgical, medical, and rehabilitative therapies have improved the prognosis for many children with spina bifida. Some individuals with this condition have normal intelligence and can lead independent lives.

Public attention has recently been focused on the second group of cases—infants who have both a correctable life-threatening defect *and* a permanent, irremediable handicap that is not life-threatening, such as mental retardation.[24] One well-known example is Down Syndrome, which occurs once in about every 700 live births.[25] Individuals with Down Syndrome are mentally retarded, although the precise extent of retardation cannot be determined in early infancy.[26] Babies with this

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[21] Barbara R. Migeon, *Genetic Problems Affecting Infants*, in Y. Edward Hsia *et al.*, eds., COUNSELING IN GENETICS, Alan R. Liss, Inc., New York (1979) at 114-15.

[22] Aubrey Milunsky and Elliot Alpert, *Maternal Serum AFP Screening*, 298 NEW ENG. J. MED. 738 (1978).

[23] One NTD that precludes development of consciousness, anencephaly, is discussed in Chapter Five *supra*.

[24] *See* notes 5 and 7 *supra*.

[25] William L. Nyhan and Nadia O. Sakati, GENETIC AND MALFORMATION SYNDROMES IN CLINICAL MEDICINE, Year Book Med. Pub., Inc., Chicago (1976) at 21. *See also* William L. Nyhan and Edward Edelson, THE HEREDITY FACTOR, Grosset & Dunlap, New York (1976) at 128-9.

[26] Although IQs from about 18-92 have been reported, most Down

syndrome often have other congenital defects, particularly cardiac abnormalities. Most Down Syndrome infants do not require any unusual medical care at birth, but a minority have a complication that would be fatal unless surgically corrected during the first year of life. The two most common problems are gastrointestinal blockage and congenital heart defects. Children with an obstruction at the outlet of the stomach, for example, cannot be fed; untreated, they would develop a fatal pneumonia or starve to death. Surgical repair of this defect, however, is typically successful.

Response of the Health Care System

Neonatal intensive care. The history of special care for unhealthy newborns began just over a century ago when Dr. E. Tarnier installed in his Paris clinic what he called "warming chambers" for premature infants.[27] The modern, high-technology neonatal intensive care units that are widespread today—there are at least 7500 NICU beds in approximately 600 hospitals across the country—were first established in the 1960s.[28] The proposal to have neonatology be a subspecialty of pediatrics was made in 1960[29]; since the first neonatology certification examinations by the American Board of Pediatrics (in 1975), over 1000 neonatologists have been certified.[30]

Syndrome children have an IQ between 30 and 55; quite a few score less than 30 and only in rare cases does the IQ exceed 70. ("Normal" IQ is from 80-120.) Hans Zellweger and Victor Ionasescu, *Genetics of Mental Retardation*, in Charles H. Carter, ed., MEDICAL ASPECTS OF MENTAL RETARDATION, Charles C. Thomas, Springfield, Ill. (2nd ed. 1978) at 160. The higher scores occur in a small percentage of the cases in which all of the person's cells do not carry the chromosomal aberration, a condition known as mosaicism. Karol Fisher, Richard Koch, and George N. Donnell, *Comparison of Mental Development in Individuals with Mosaic and Trisomy 21 Down's Syndrome*, 58 PEDIATRICS 744 (1976).

[27] While these new devices proved useful in clinics, they also caught the public's imagination when their use was demonstrated in international expositions over the years. At the Berlin exposition in 1896 they were dubbed "child hatcheries" (kinderbrutanstalt). Incubator-baby exhibits were popular in America as late as 1939 (the New York World's Fair). William A. Silverman, *Incubator Baby Side Shows*, 64 PEDIATRICS 127 (Aug. 1979).

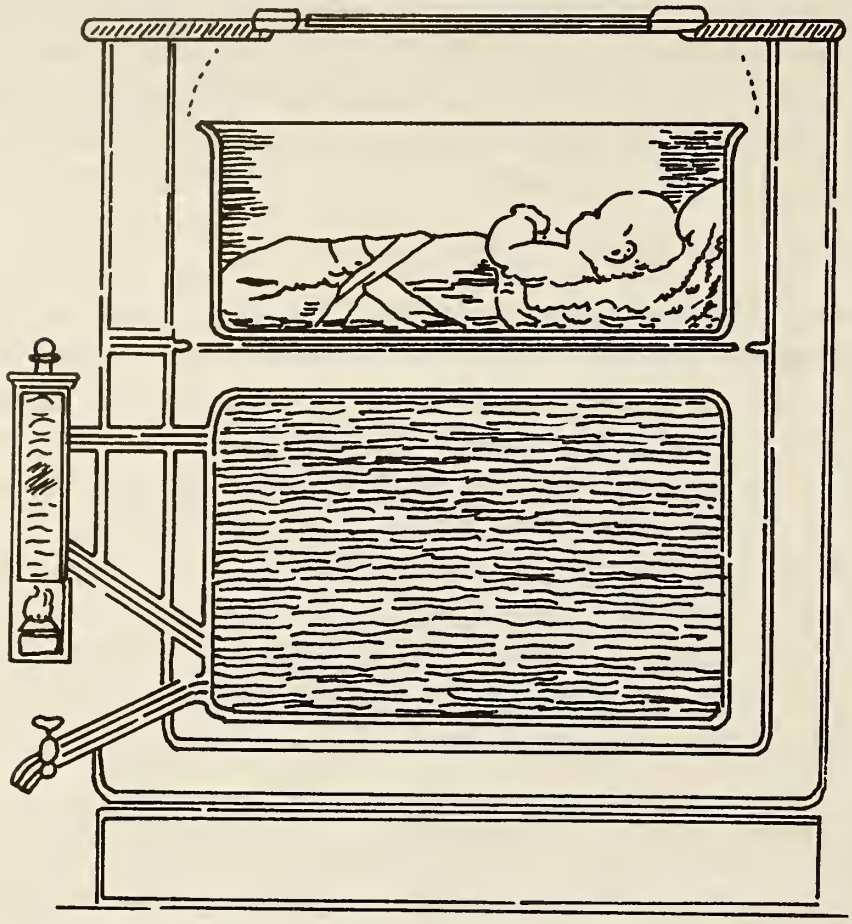
[28] COST OF NEONATAL CARE, *supra* note 11, at 7 and 15. During the 1970s, nearly every state passed legislation mandating that private insurance cover neonatal intensive care, which probably helped ensure that NICUs would become available. David T. Deal, *Bioethical Implications of Health Care Insurance for Newborns: A Comparative Analysis of Fifty States' Law*, unpublished manuscript (April 1978).

[29] Edward R. Schlesinger, *Neonatal Intensive Care: Planning for Services and Outcomes Following Care*, 82 J. PEDIATRICS 916 (1973).

[30] Information provided by personal communication with Anne Justus, American Board of Pediatrics (Jan. 1983).

Figure 2: Tarnier-Martin Couveuse (1880).

Source: William A. Silverman, Incubator Baby Side Shows, 64 PEDIATRICS 127, 28 (1979). *Copyright American Academy of Pediatrics 1979.*



An estimated 6% of live-born infants go to a neonatal intensive care unit, where the length of stay averages 8-18 days.[31] The cost of such high-technology care is estimated at $8000 for an average case; in 1978, $1.5 billion was spent on NICU care.[32]

The introduction of NICUs has coincided with a dramatic decrease in mortality during the first month of life. Most of this improvement is due to better survival rates for LBW infants rather than to a change in the proportion of high-risk births.[33] Although the effectiveness of NICUs has not been determined directly by clinical trials, the improvements in birth-weight-specific mortality together with other relevant data suggest

[31] COST OF NEONATAL CARE, *supra* note 11, at 15.

[32] *Id.* at 19.

[33] For a summary of data on the effectiveness of NICUs, see Budetti and McManus, *supra* note 2; Nigel Paneth *et al., Newborn Intensive Care and Neonatal Mortality in Low-Birth-Weight Infants*, 307 NEW ENG. J. MED. 149 (1982).

that NICUs have played an important role in those reductions.[34]

Although NICU treatment saves many seriously ill newborns, it can be both a painful experience for the infant and an anguishing one for parents and care givers. Watching the suffering of an infant the size of an adult's hand—connected to awesome machinery and offered only distant prospects of somewhat normal survival—inevitably takes an emotional toll.[35] Some NICUs assign certain staff members to support and counsel parents and to arrange support programs for the NICU staff.[36]

Post-hospital needs. The societal commitment to save the lives of seriously ill newborns is dramatically illustrated by the high technology of the NICU. The resources and energy expended and the emotional strains endured attest to the high value placed on providing some of society's most vulnerable members with the opportunity to live and thrive. But the needs of these children do not end with their discharge from the hospitals; many survivors have long-term diseases or handicaps.[37]

The potential that the NICU has fought to preserve for these children can only be realized if support is sufficient after they leave the hospital. Their families must often travel a financially and emotionally perilous path to realize that potential.[38] Physically handicapped youngsters, for example,

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[34] *See, e.g.*, John C. Sinclair *et al., Evaluation of Neonatal-Intensive Care Programs*, 305 New Eng. J. Med. 489 (1981).

[35] *See, e.g.*, Robert and Peggy Stinson, *On the Death of a Baby*, Atlantic Monthly (July 1979), reprinted with commentary in 7 J. Med. Ethics 5 (1981). A longer treatment of this case was published since: Robert and Peggy Stinson, The Long Dying of Baby Andrew, Little, Brown, Boston (1983). The Stinsons describe their emotional ordeal as they watched a series of hopeless "treatments" result in increased pain and suffering for their dying premature infant.

[36] The Commission heard testimony from Carole Kennon, for example, on her role as a social worker with the NICU at Children's Hospital National Medical Center. Transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 9.

[37] For example, low birth weight infants are more likely to experience visual, hearing, respiratory, and neurological problems and other morbidity as they grow. Costs of Neonatal Care, *supra* note 11, at 34-38.

[38] Even when families have good insurance coverage, the costs can be significant. A small copayment for each procedure can result in large out-of-pocket payments and some costs (such as some special child care and education, transportation to major medical centers for treatment, and the loss of a wage earner to child care responsibilities) are not included in insurance coverage. Altogether, the expenses can total thousands or even tens of thousands of dollars. *See, e.g.*, Anne Norman, *The High Cost of Saving Ultra-Premies* (Letter), 3 Science82 22 (Oct. 1982); public funding has eased this burden in many cases and

need long-term training for ambulation and independence; the development of mentally retarded children can be greatly enhanced by intensive stimulation, particularly when begun at a very young age.[39] Studies show that appropriate early intervention is cost-effective, yet it is sometimes difficult to obtain or pay for these services.[40]

Handicapped children and their families may also need counseling to help them respond productively to their difficulties, including the stress placed on the marriage and on family life.[41] In addition to professional assistance, parents and

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allowed families to obtain services. Private charitable organizations also play a crucial role in raising funds and providing services for the handicapped. In expanding the opportunities for the disabled, public and charitable programs often ultimately reduce societal costs. George R. Dunlop, *Remedies as Ills*, 64 BULL. AM. COLL. SURGEONS 2 (Dec. 1979).

[39] Jane E. Brody, *Personal Health*, N. Y. TIMES, Dec. 22, 1982, at C-8; Norris G. Haring and Alice H. Hayden, *Effectiveness and Cost-Efficiency of Early Intervention with Handicapped Children*, Hearing before Subcomm. on the Handicapped, Comm. on Labor and Human Resources, U.S. Senate (April 30, 1981) at 115; Inter-Act (The National Committee for Services to Very Young Children with Special Needs and Their Families), EARLY INTERVENTION FOR CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES: FINDINGS AND RECOMMENDATIONS, WESTAR Series Paper #11 (June 1981).

[40] Federal laws have affirmed the rights of the handicapped and resulted in Federal funds for educational programs and research. A significant portion of Federal funding for service and education is distributed to localities in several different block grants (*e.g.*, maternal-child health, preventive programs, etc.). Under this program, states have the option of allocating some or all of the funds either for services to the handicapped or to other programs in the block grant category. *See generally* Hearing before Subcomm. on the Handicapped, *supra* note 39.

Although a few states mandate comprehensive services, in most jurisdictions the handicapped compete with other social service groups for scarce discretionary funds. Even within the handicapped community there is competition since the type of services needed varies enormously depending on the type and severity of the disability.

[41] Albert J. Solnit and Mary H. Stark, *Mourning and the Birth of a Defective Child*, 16 THE PSYCHOANALYTIC STUDY OF THE CHILD (journal) 523 (1961); Elizabeth D'Arcy, *Congenital Defects: Mothers' Reactions to First Information*, 3 BRIT. MED. J. 796 (1968); Dennis Drotar *et al., The Adaptation of Parents to the Birth of an Infant with Congenital Malformation: A Hypothetical Model*, 56 PEDIATRICS 710 (1975); N. Johns, *Family Reactions to the Birth of a Child with a Congenital Anomaly*, 5 MED. J. AUST. 277 (1971); John H. Kennell and Marshall H. Klaus, *Caring for Parents of an Infant Who Dies*, in Marshall H. Klaus and John H. Kennell, eds., MATERNAL-INFANT BONDING, C.V. Mosby, St. Louis (1976) at 202; D. Gary Benfield *et al., Grief Response of Parents*

siblings often benefit greatly from support groups whose members share similar experiences and helpful suggestions.

Current Decisionmaking Practices

Physicians' Views. A major stimulus to the ethical and legal debate on foregoing life-sustaining treatment for newborns was provided by a 1973 medical journal article that described how and why nontreatment had been chosen for 43 of the 299 babies who died in a 30-month period in the intensive care nursery of Yale-New Haven Hospital.[42] The decision against treatment followed deliberations in which "parents and physicians... concluded that prognosis for meaningful life was extremely poor or hopeless."[43] The authors argued strongly for leaving such decisions to parents and physicians.

Other physicians confirmed that decisions to forego therapy are part of everyday life in the neonatal intensive care unit; with rare exceptions, these choices have been made by parents and physicians without review by courts or any other body.[44] This approach has been endorsed by the American Medical Association, whose Judicial Council holds that "the decision whether to exert maximal efforts to sustain life [of seriously deformed newborns] should be the choice of the parents."[45]

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to Neonatal Death and Parent Participation in Deciding Care, 62 PEDIATRICS 171 (1978); Catherine LaRoche *et al., Grief Reactions to Perinatal Death: An Exploratory Study*, 23 PSYCHOSOMATICS 510 (1982).

[42] Duff and Campbell, *supra* note 4.

[43] *Id.* at 890.

[44] Well, we at Children's Hospital have to make the decision to forego life-sustaining therapy in about 40 to 45 cases per year. And I want to impress upon you we get some of the sickest infants in the area, that it is not really a well premature infant. And if it sounds like a lot of cases it is, because we get the sickest ones....We are talking about a total population of admission rates to the intensive care unit of approximately 400 infants. Of those 400 infants, about a third of them die, so we are talking about perhaps a hundred-and-some-odd deaths, and out of those perhaps about half we make the decision to stop. It is not that those infants might not—and particularly with some of the intraventricular bleeds, they might go on to die on their own a week later or two weeks later or three weeks later.

Testimony of Dr. Anne Fletcher, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 8, 26; Dr. Robert E. Cooke, Statement before *Hearing on Medical Ethics: The Right to Survival*, Subcomm. on Health, Comm. on Labor and Public Welfare, U.S. Senate (1974) at 26.

[45] Judicial Council of the American Medical Association, CURRENT OPINIONS, American Medical Association, Chicago, (1982) at 9, *reprinted in* Appendix C, pp. 299-300 *infra*.

Surveys of physicians show that most would follow parental wishes to stop treatment for at least some abnormal infants. When California pediatricians were polled in 1975 about how they would treat a Down Syndrome baby with a life-threatening intestinal obstruction (assuming parental agreement and immunity from existing laws), 17% said they would do "everything humanly possible" to save the baby's life, while 61% would give ordinary medical care but "nothing heroic" (meaning the baby would die without the operation to remove the obstruction).[46] In a national study in 1977, pediatricians and pediatric surgeons were asked whether they would acquiesce in a parental decision not to treat a Down Syndrome infant having congenital heart disease.[47] Even though immunity from the law was not mentioned, 85% of the pediatric surgeons responding and 65% of the pediatricians said they would follow the parents' wishes. A third study found that 51% of the pediatricians surveyed in Massachusetts would not recommend surgery for a Down Syndrome infant with intestinal blockage.[48]

Data from these interviews and surveys risk revealing only what people think they would or should do, rather that what those who have been faced with such a choice actually do. A recent Connecticut Department of Health Services study of actual decisionmaking practices for newborns—which included reviews of all deaths in an NICU for six months and of death certificates for 20 newborns, as well as interviews with families and professionals—revealed that "actual practices are remarkably consistent throughout the state."[49] Only two cases were found in which treatment was continued over parental objections and only two in which there was any suspicion that the child's interests were not being advanced. It found that teams of providers "consult continually about the patient's condition" before "decisions become recommendations to parents for the treatment of their infants."[50]

Shortcomings of the Present System. Despite reports of occasional cases in which seriously erroneous decisions about

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[46] *Treating the Defective Newborn: A Survey of Physicians' Attitudes*, 6 HASTINGS CTR. REP. 2 (April 1976).

[47] Anthony Shaw, Judson G. Randolph, and Barbara Manard, *Ethical Issues in Pediatric Surgery: A National Survey of Pediatricians and Pediatric Surgeons*, 60 PEDIATRICS 588 (Supp. 1977).

[48] David Todres *et al., Pediatricians' Attitudes Affecting Decision-Making in Defective Newborns*, 60 PEDIATRICS 197 (1977).

[49] Thayer Baldwin, Jr., *Infant Death: Life and Death in Newborn Special Care Units*, Bureau of Health System Regulation, Connecticut State Dept. of Health Services, mimeo. (March 1982) at 5.

[50] *Id.*

the treatment of newborns were carried out, such events appear to be very rare.[51] Nonetheless, a number of shortcomings in current decisionmaking about seriously ill newborns are apparent:

- appropriate information may not be communicated to all those involved in the decision;
- professionals as well as parents do not at times understand the bases of a decision to treat or not to treat; and
- actions can be taken without the informed approval of parents or other surrogates.

Communication. Given the complexity of the situation it is hardly suprising that communication problems arise in decisionmaking about life-support for critically ill infants. As the Connecticut study found, however, the problems are much more than technical ones:

> All parties interviewed felt that our society and the providers have not done enough to communicate information necessary for decisionmaking to the parents. Providers may choose not to discuss some considerations because of their concern about the capacity of distraught parents to comprehend and absorb complex and technical information; however, the most frequently cited insufficiency derives from preconceptions held by the physicians and parents about the quality of life of handicapped individuals.[52]

Unfortunately, the circumstances in which many of these decisions have to be made compound the barriers to communication: the family may not live close to the tertiary care institution where the infant is being treated; often the family's life is highly disrupted, especially when there are other children and when the birth was a complicated one and the

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[51] Of the more than three million babies born each year in the United States, tens of thousands are born prematurely or with congenital anomalies and many of them would die quickly if not treated. Yet it is rare for treatment not to be provided when it is predicted to provide a means of remedying the medical problem; the cases when approval for such treatment is denied are few enough to be newsworthy. While very disturbing, they may be inevitable in a society that treasures personal and familial autonomy. Greater control by state officials, in the name of protecting the helpless, would actually be warranted only if it clearly saved more lives. Furthermore, such steps would raise problems of governmental intrusion into private matters in many cases where no better decision could be made. See pp. 219-23 *infra*.

[52] Baldwin, *supra* note 49, at 6. One couple, troubled by the experiences they had with their severely ill son, called for better ways to make decisions about treatment. "We regard any decision making by concerned physician and parents behind closed doors of the pediatric unit as a haphazard approach." Bridge and Bridge, *supra* note 5, at 19.

mother remains hospitalized; and there are so many interrelated decisions about care that have to be made on a continuous basis that it is hard to convey all the relevant facts and probabilities to anyone not constantly involved in the situation. For these and other reasons, the teams of nurses, physicians, and other specialists in NICUs develop patterns for dealing with—and categorizing—patients.[53] Although pressure from parents to communicate more information is not necessarily resisted, especially if the NICU team is comfortable with the way the parents are using the information, team members can seldom take the time to understand the background of the family or see the situation from the parent's perspective.

Understanding. It is not only parents who have a hard time with the decisions to be made. On interviews conducted for a study of the treatment of critically ill patients, some physicians said they would be unable to comply with a parental request to withdraw life-sustaining treatment yet were unable to give any reason for their position.

> Those who indicated that they would treat such infants [anencephalics] were asked to explain why. Few of them could offer an explicit rationale. In general, it appeared that those who would treat such a child did so because the idea of withdrawing therapy was simply unthinkable. Very few doctors seemed to have given such matters enough consideration to have worked out a philosophical position toward them.[54]

Some decisions are even made by default.

> Each time we discussed it [whether or not to resuscitate a child with severe problems] we were unable to make a decision so that when the child stopped breathing we did resuscitate because we hadn't decided not to.[55]

Approval. Physicians sometimes believe they must make the decisions because the parents will feel guilty over anything less than an optimal outcome for the baby.[56] Taking responsi-

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[53] "Babies are not just babies. A particular baby fits into a loose typology that is part of the staff's way of seeing things." Robert Bogdan, Mary Alice Brown, and Susan Bannerman Foster, *Be Honest but Not Cruel: Staff/Parent Communication on a Neonatal Unit*, 41 HUMAN ORGANIZATION 6, 7 (1982).

[54] Diana Crane, THE SANCTITY OF SOCIAL LIFE: PHYSICIANS' TREATMENT OF CRITICALLY ILL PATIENTS, Russell Sage Foundation, New York (1975) at 76.

[55] *Id.* at 81.

[56] And at the end of this, I feel it is important, and I think we as a team feel it is important, that we make a recommendation of what is to be done. That is not to say that we don't feel the parents have a decision to make, but it is a decision with us and not a decision on their own. And we usually have felt it is our duty to make a decision, and then have them agree with us,

bility for the decision is sometimes difficult to separate psychologically from being responsible for the medical condition.[57] Providers may try to shield parents from this guilt. If this removes parents' control of decisionmaking, however, the child loses the protection of its surrogates. Moreover, as one parent told the Commission:

> I am very uncomfortable with the doctor assuming that if there are two equal things, he will decide and take the responsibility. I think when you become a parent, and I am an adopted parent, so I feel that responsibility even more—I had assumed there would be hard decisions to make, and some of them were harder than I had anticipated. But nonetheless, I felt that was a responsibility I took for myself. And I don't want to turn it over to somebody who is going to spare me that.[58]

Some physicians have trouble simultaneously allowing parents to retain control of decisionmaking and sharing the burdens of responsibility.

Unfortunately, manipulations of the situation are occasionally made for the benefit of the health care professionals instead of the parents.

> Consultation with the family is used in part as a method of insuring that they will accept the decision and not take legal action against the physician later. It is not considered appropriate for the family to make the final decision.[59]

Additionally, parents may be excluded from the decisions entirely or presented with a narrower range of "choices" than is appropriate.[60]

The Legal Framework. Even when these shortcomings are overcome, conscientious health care teams still face serious problems such as parents who are incapable or unwilling to participate in decisionmaking or who make what seem to the team to be decisions that are substantially harmful to the child.

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rather than to have them feel they made the decision completely on their own.

Fletcher, *supra* note 44, at 17.

[57] Bogdan, Brown, and Foster, *supra* note 53; Fletcher, *supra* note 44, at 8.

[58] Testimony of Minna Nathanson, transcript of 17th meeting of the President's Commission (Feb. 12, 1982) at 153.

[59] Crane, *supra* note 54, at 74.

[60] *See* Stinson and Stinson, *supra* note 35, and Bridge and Bridge, *supra* note 5.

Although health care professionals and institutions are reluctant to become enmeshed in legal proceedings,[61] in certain cases they may feel they have no choice but to enter that arena, with all the new uncertainties and difficulties that will create for their treatment of the infant in question.

The paucity of directly relevant cases makes characterization of the law in this area somewhat problematic, but certain points stand out. First, there is a presumption, strong but rebuttable, that parents are the appropriate decisionmakers for their infants.[62] Traditional law concerning the family, buttressed by the emerging constitutional right of privacy, protects a substantial range of discretion for parents.[63] Second, as persons unable to protect themselves, infants fall under the *parens patriae* power of the state. In the exercise of this authority, the state not only punishes parents whose conduct has amounted to abuse or neglect of their children but may also supervene parental decisions before they become opera-

[61] In a national survey, pediatricians and pediatric surgeons who were asked to rank the importance of possible decisionmakers placed courts at a distant fourth behind parents, doctors, and hospitals ethic committees. Shaw, Randolph, and Manard, *supra* note 47, at 591.

[62] The common-law antecedents of this presumption are largely to be found in a notion of paternal (and later parental) supremacy in family matters and in the corollary that children had few, if any, rights as persons, being regarded in law as chattels. These antecedents are now largely discredited and rejected, and have been supplanted by a tempered right of parental autonomy. This right has gradually developed under a constitutional aegis in this century, guided largely by principles of religious freedom and due process until the 1960s. *See, e.g.*, Meyer v. Nebraska, 262 U.S. 390 (1923) (right to raise child); Pierce v. Society of Sisters, 268 U.S. 510 (1925) (parents' rights to control education of their children). *Cf.* Prince v. Mass., 321 U.S. 158 (1944) (parental authority to have child religious literature circumscribed). More recently the theory began to be influenced by, if not assimilated to, the developing constitutional right of privacy. Wisconsin v. Yoder, 406 U.S. 205 (1972) (parents' right to direct religious upbringing of children). *See* pp. 31-32 (discussion of right of privacy).

[63] Familial privacy has received increasing protection from law throughout this century. In the earlier stages of legal development, the source of this protection was sometimes found in the constitutional right of religious freedom; it has gradually evolved into a more secular protection generally referred to as the right of privacy. The substantive core includes the authority of parents to establish family values, to set goals for the family and for its individual members, and to make decisions affecting the welfare of family members free from interference by agencies of the state. For example, although the law requires that children go to school, parents can generally choose the school. Parents must provide adequate food and shelter, but they need not conform to the opinions of others as to the best food or the most appealing shelter. The society as a whole benefits from promoting diversity, and privacy law has played an increasing role in protecting diverse life-styles and values.

tive to ensure that the choices made are not so detrimental to a child's interests as to amount to neglect and abuse.[64]

Plainly, these two legal doctrines—respect for parental discretion and protection of children against harm—pull in opposite directions and it is often difficult to know how to reconcile them in a particular case. These difficulties may partially account for the dispute over what constitutes "neglect and abuse." The meaning of these terms has varied over time and has rarely been the subject of careful legislative definition in statutes.[65] Yet although the standards remain vague even in the medical arena, as long as parents choose from professionally accepted treatment options the choice is rarely reviewed in court and even less frequently supervened.[66] The courts have exercised their authority to appoint a guardian for a child when the parents are not capable of participating in decisionmaking or when they have made decisions that evidence substantial lack of concern for the child's interests.[67] Although societal

[64] *See, e.g., Model Child Protection Act* (1983), *reprinted in* Appendix H, pp. 478-93 *infra*.

[65] Note, *State Intrusion into Family Affairs*, 26 STAN. L. REV. 1383 (1974); Judith Areen, *Intervention Between Parent and Child: A Reappraisal of the State's Role in Child Absue and Neglect Cases*, 63 GEO. L. J. 887, 891 (1975); Michael Wald, *State Intervention on Behalf of "Neglected" Children: A Search for Realistic Standards*, 27 STAN. L. REV. 985 (1975).

[66] Generally, when the medical treatment at issue for a minor child is for a disease or condition that is not severe or life-threatening, courts will accede to parental wishes not to treat even when physicians disagree. The courts have been particularly reluctant to order treatment when it is possible to delay the decision until the child reaches the age of majority. *See, e.g,, In re* Seiferth, 309 N.Y. 80, 127 N.E.2d 820 (1955) (surgery not ordered for 14-year-old boy with cleft palate), *In re* Green, 220 Pa. Super. Ct. 191, 286 A.2d 681 (1971) (surgery to correct spinal curvature). Likewise, even when the consequences of foregoing treatment may be grave, courts have refused to order treatment where parents have had well-grounded concerns that the risks outweigh the possible benefits. *In re* Tuttendario, 21 Pa. Dist. 561 (1912) (treatment for rickets may have been more dangerous than the disease); *In re* Hudson, 13 Wash.2d 673, 126 P.2d 765 (1942) (surgery for greatly enlarged and useless arm with "gross possibility of fatality"). *But see, In re* Sampson, 29 N.Y.2d 900, 279 N.E.2d 918, 328 N.Y.S.2d 686 (1972) (over parental objection, court ordered surgery for 15-year-old boy with neurofibromatosis whom the court described as grotesque and repulsive), *criticized in* Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervention of Parental Autonomy*, in Willard Gaylin and Ruth Macklin, eds., WHO SPEAKS FOR THE CHILD, Plenum Press, New York (1982) at 153, 180-84.

[67] By far, most of the cases involving judicial inquiry into parents' medical choices for their children have occurred in situations in which parents have opted for unconventional "medical" care for their children (such as laetrile for the treatment of cancer; *see, e.g.*, Custody of a Minor, 393 N.E.2d 836 (Mass. 1979)). When there has been a

involvement usually occurs under the auspices of governmental instrumentalities—such as child welfare agencies and courts—the American legal system ordinarily relies upon the private initiative of individuals, rather than continuing governmental supervision, to bring the matter to the attention of legal authorities.[68]

An Ethical Basis for Decisionmaking

Since newborns are unable to make decisions, they will always need a surrogate to decide for them.[69] In nearly all cases, parents are best situated to collaborate with practitioners in making decisions about an infant's care,[70] and the range of choices practitioners offer should normally reflect the

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medically accepted treatment likely to be of help to the child whose life is in danger the courts have ordered treatment over parental objection. *See, e.g., In re* Pogue, No. M-18-74 (Super. Ct. D.C. Nov. 1, 1974) (blood transfusion ordered for otherwise healthy baby over objection of Jehovah's Witness parents); Raleigh Fitkin-Paul Morgan Mem. Hosp. v. Anderson, 42 N.J. 421, 201 A.2d 537, *cert. denied*, 377 U.S. 985 (1964) (transfusion needed at birth); Hoener v. Bertinato, 67 N.J. Super. 517, 171 A.2d 140 (Juv. & Dom. Rel. Ct. 1961). When the only treatments available have been novel or of great risk the courts have acquiesced in parental decisions to forego treatment. *In re* Green, 12 Crime & Delinquency 377 (Child Div., Milwaukee County Ct. Wis. 1966) (court would not order child to have controversial treatment for sickle-cell anemia for which mother had not consented).

[68] "Indeed, a significant number of care and protection petitions are initiated by hospitals or members of their staffs, since they are often the only persons outside the family in a position to detect signs of abuse, neglect, or abandonment." Cited in Custody of a Minor, 434 N.E.2d 601, 607 (Mass. 1982).

[69] *See* pp. 126-31 *supra*, and the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions, U.S. Government Printing Office, Washington (1982) at 181-88, for a general discussion of the designation and role of surrogates.

[70] There are any number of explanations for this societal allocation of authority: respect for the family and a desire to foster the diversity which it brings; the fitness of giving the power to decide to the same people who created the child and have the duty to support and protect him; the belief that a child cannot be much harmed by parental choices which fall within the range permitted by society and a willingness to bear the risks of harm this allocation entails or a belief that in most cases "harm" would be hard for society to distill and measure anyway; or simply the conclusion that the administrative costs of giving authority to anyone but the parents outweigh the risks for children and for society unless the parents are shown to be unable to exercise their authority adequately.

A. M. Capron, *Legal Considerations Affecting Clinical Pharmacological Studies in Children*, 21 Clinical Research 141, 146 (1972).

parents' preferences regarding treatment (see Table 1, p. 218). Parents are usually present, concerned, willing to become informed, and cognizant of the values of the culture in which the child will be raised. They can be expected to try to make decisions that advance the newborn's best interests. Health care professionals and institutions, and society generally, bear responsibility to ensure that decisionmaking practices are adequate.

Parental Autonomy and Countervailing Considerations. Families are very important units in society. Not only do they provide the setting in which children are raised, but the interdependence of family members is an important support and means of expression for adults as well. Americans have traditionally been reluctant to intrude upon the functioning of families, both because doing so would be difficult and because it would destroy some of the value of the family, which seems to need privacy and discretion to maintain its significance.[71] Parents and a child's physician may choose, for example, to correct a disfiguring birthmark or not, to have a generalist or a specialist attend to an injury, or to accept or reject hospitalization for many illnesses. Public policy should resist state intrusion into family decisionmaking unless serious issues are at stake and the intrusion is likely to achieve better outcomes without undue liabilities.

When parental decisonmaking seems not to take account of a child's best interest, however, the stage is set for public intervention. This issue has usually arisen in cases in which the parent's values differ from those common in society. For example, parents are free to inculcate in their children a religious belief that precludes the acceptance of transfused blood. But when a transfusion is necessary for the success of surgery that would be life-saving or without which a child would suffer substantial, irreversible harm, parents' prerogatives must yield to the child's interest in life or in leading a reasonably healthy life.[72] Parents are not, as the Supreme Court has stated, entitled to make martyrs of their children.[73]

The growth of neonatal intensive care has posed problems for parental decisionmaking in addition to those arising from

[71] Margaret O'Brien Steinfels, *Children's Rights, Parental Rights, Family Privacy, and Family Autonomy*, in Gaylin and Macklin, *supra* note 66, at 223.

[72] Although some of the earlier cases were rooted in religious claims, others—including a companion case to *Pierce*—were rooted in liberty interests. *See* Pierce v. Hill Military Academy, 268 U.S. 510 (1925). Since the enunciation of a constitutional right of privacy in Griswold v. Connecticut, 381 U.S. 479 (1965), and its subsequent growth, claims of parental autonomy now seem more appropriate to be couched in those terms.

[73] Prince v. Massachusetts, 321 U.S. 158, 166 (1944).

unusual beliefs. Parents may be reeling emotionally from the shock of having a seriously ill child instead of the normal, healthy infant they had imagined. Assuming they have had no previous experience with the condition in question, they are likely to be poorly informed about long-term prospects for the child, be subject to pressing financial exigencies, and be worried about effects on siblings and the family as a whole. Furthermore, the infant's condition may require rather urgent response, often while the mother is still recovering from delivery.

Yet, with suitable assistance, most parents can overcome these difficulties and make decisions on the child's behalf in an appropriate fashion. In order to make good decisions, parents must be told the relevant information, including as accurate an appraisal of prognosis as possible. The medical information they receive, including its uncertainties, should be up-to-date.[74] Their consideration of the situation may be helped by the opportunity to talk with other parents who have faced such decisions, with consultant medical specialists, and perhaps with religious advisors.[75] When reasonably possible, procedures should be used to sustain the infant's life long enough to avoid undue haste in decisionmaking.[76]

If parents continue to insist on a course of action that presents a substantial risk of seriously jeopardizing the infant's best interests, prompt intrainstitutional review should occur. When a decision consistent with the child's interests is still not reached, the health care provider should seek to have a court appoint a surrogate in place of the parents, on the grounds that the parents are incapacitated to make the decision, unable to agree, unconcerned for the infant's well-being, or acting out of an interest that conflicts with the child's.[77]

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[74] *See, e.g.*, Herman A. Hein, Christina Christopher, and Norma Ferguson, *Rural Perinatology*, 55 PEDIATRICS 769 (1975); Herman A. Hein, *Evaluation of a Rural Perinatal Care System*, 66 PEDIATRICS 540 (1980).

[75] John C. Fletcher, COPING WITH GENETIC DISORDERS: A GUIDE FOR CLERGY AND PARENTS, Harper & Row, New York (1982).

[76] John A. Robertson, *Dilemma in Danville*, 11 HASTINGS CTR. REP. 5, 6 (Oct. 1981).

[77] There are no reported appellate cases of this type, but a few trial court decisions have overridden parental refusals of treatment of their defective newborn children. *See, e.g.*, Maine Medical Center v. Houle, No. 74-145 (Cumberland County Super. Ct., Maine, Feb. 14, 1974) (court order to repair meningomyelocele mooted by baby's death); *In re* Cicero, 101 Misc.2d 699, 421 N.Y.S.2d 965 (Sup. Ct. Bronx County, 1979) (parental refusal to treat meningomyelocele overridden). *In re* Elin Daniel, Case No. 81-15577 FJO1 (Miami, Fla., June 23, 1981); *Court-Ordered Surgery on Baby Held Success*, N.Y. TIMES, Sept. 18, 1981, at A-9.

Besides information, parents need empathy and understanding; health care professionals face the difficult task of keeping lines of communication open with parents who are often unsure of their own feelings and abilities to cope with this tragedy, uncomfortable in the hospital environment, and burdened by other practical barriers to participating in their child's care. Yet these difficulties should not lead to a hasty judgment that parents are uninterested in a child's welfare or incapable of good decisionmaking.[78] Great efforts must be made to understand parents' values and improve their ability to decide on a course of action. In cases when parents are not present, a suitable surrogate from within the family might well be available (for example, the grandmother of the baby of an adolescent mother), but an infant without family surrogates will always need to have another guardian named.

Best Interests of the Infant. In most circumstances, people agree on whether a proposed course of therapy is in a patient's best interests. Even with seriously ill newborns, quite often there is no issue—either a particular therapy plainly offers net benefits or no effective therapy is available. Sometimes, however, the right outcome will be unclear because the child's "best interests" are difficult to assess.

The Commission believes that decisionmaking will be improved if an attempt is made to decide which of three situations applies in a particular case—(1) a treatment is available that would clearly benefit the infant, (2) all treatment is expected to be futile, or (3) the probable benefits to an infant from different choices are quite uncertain (see Table 1, p. 218). The three situations need to be considered separately, since they demand differing responses.

Clearly beneficial therapies. The Commission's inquiries indicate that treatments are rarely withheld when there is a medical consensus that they would provide a net benefit to a child. Parents naturally want to provide necessary medical care in most circumstances, and parents who are hesitant at first about having treatment administered usually come to recognize the desirability of providing treatment after discussions with physicians, nurses, and others. Parents should be able to choose among alternative treatments with similarly

[78] With some exceptions...the staff's assessment of parents and parents' dispositions toward their babies and the degree to which parents are understanding what is being told to them is often inaccurate. Most assessments of parents are based on limited knowledge, derived mainly from short observations, limited conversations, or secondhand reporting of incidents and information. What is known is episodic, not informed by the context of the perinatal experience in the lives of the parents.

Bogdan, Brown, and Foster, *supra* note 53, at 11.

Table 1:

Treatment Options for Seriously Ill Newborns—Physician's Assessment in Relation to Parent's Preference

Physician's Assessment of Treatment Options*	Parents Prefer to Accept Treatment**	Parents Prefer to Forego Treatment**
Clearly beneficial	Provide treatment	Provide treatment during review process††
Ambiguous or uncertain	Provide treatment	Forego treatment
Futile	Provide treatment unless provider declines to do so†	Forego treatment

* The assessment of the value to the infant of the treatments available will initially be by the attending physician. Both when this assessment is unclear and when the joint decision between parents and physician is to forego treatment, this assessment would be reviewed by intra-institutional mechanisms and possibly thereafter by court.

** The choice made by the infant's parents or other duly authorized surrogate who has adequate decisionmaking capacity and has been adequately informed, based on their assessment of the infant's best interests.

† See p. 220 *infra*.

†† See pp. 218-19 *infra*.

beneficial results and among providers, but not to reject treatment that is reliably expected to benefit a seriously ill newborn substantially, as is usually true if life can be saved.

Many therapies undertaken to save the lives of seriously ill newborns will leave the survivors with permanent handicaps, either from the underlying defect (such as heart surgery not affecting the retardation of a Down Syndrome infant) or from the therapy itself (as when mechanical ventilation for a premature baby results in blindness or a scarred trachea). One of the most troubling and persistent issues in this entire area is whether, or to what extent, the expectation of such handicaps should be considered in deciding to treat or not to treat a seriously ill newborn. The Commission has concluded that a very restrictive standard is appropriate: such permanent handicaps justify a decision not to provide life-sustaining treatment only when they are so severe that continued existence would not be a net benefit to the infant. Though inevitably somewhat subjective and imprecise in actual application, the concept of "benefit" excludes honoring idiosyncratic views that might be allowed if a person were deciding about his or her own treatment. Rather, net benefit is absent only if

the burdens imposed on the patient by the disability or its treatment would lead a competent decisionmaker to choose to forego the treatment. As in all surrogate decisionmaking, the surrogate is obligated to try to evaluate benefits and burdens from the infant's own perspective.[79] The Commission believes that the handicaps of Down Syndrome, for example, are not in themselves of this magnitude and do not justify failing to provide medically proven treatment, such as surgical correction of a blocked intestinal tract.

This is a very strict standard in that it excludes consideration of the negative effects of an impaired child's life on other persons, including parents, siblings, and society. Although abiding by this standard may be difficult in specific cases, it is all too easy to undervalue the lives of handicapped infants[80]; the Commission finds it imperative to counteract this by treating them no less vigorously than their healthy peers or than older children with similar handicaps would be treated.

Clearly futile therapies. When there is no therapy that can benefit an infant, as in anencephaly or certain severe cardiac deformities, a decision by surrogates and providers not to try predictably futile endeavors is ethically and legally justifiable. Such therapies do not help the child, are sometimes painful for the infant (and probably distressing to the parents), and offer no reasonable probability of saving life for a substantial period. The moment of death for these infants might be delayed for a short time—perhaps as long as a few weeks—by vigorous therapy.[81] Of course, the prolongation of life—and hope against

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[79] The importance of adopting the viewpoint of the incompetent patient, see pp. 131-36 *supra*, is especially well illustrated regarding newborns. For many adults, life with severe physical or mental handicap would seem so burdensome as to offer no benefits. However, this assessment arises largely from the adults' existing hopes and aspirations that would be forever unfulfilled. From the perspective of an infant who can be helped to develop realistic goals and satisfactions, such frustrations need not occur. In fact, many severely handicapped persons are quite successful in finding and creating meaningful lives despite various limitations. Adopting the infant's point of view requires valuing these successes equally with a more conventional ideal. *See, e.g.*, Karen M. Metzler, *Human and Handicapped*, in Samuel Gorovitz *et al.*, eds., MORAL PROBLEMS IN MEDICINE, Prentice-Hall, Inc., Englewood Cliffs, N.J. (1976) at 358.

[80] For a discussion of discrimination against handicapped, see Institute of Medicine, HEALTH CARE IN THE CONTEXT OF CIVIL RIGHTS, National Academy of Sciences, Washington (1981). *Cf.* Helge H. Mansson, *Justifying the Final Solution*, 3 OMEGA 79 (May 1972).

[81] People differ in their assessment of when a potential prolongation of life is to be taken as meaningful. The analysis in this section applies to babies whose lives will end in infancy and are likely be measured in hours or days, not years.

Medicine may *never* have all the solutions to all the problems

hope—may be enough to lead some parents to want to try a therapy believed by physicians to be futile. As long as this choice does not cause substantial suffering for the child, providers should accept it, although individual health care professionals who find it personally offensive to engage in futile treatment may arrange to withdraw from the case.[82]

Just as with older patients, even when cure or saving of life are out of reach, obligations to comfort and respect a dying person remain. Thus infants whose lives are destined to be brief are owed whatever relief from suffering and enhancement of life can be provided, including feeding, medication for pain, and sedation, as appropriate. Moreover, it may be possible for parents to hold and comfort the child once the elaborate means of life-support are withdrawn, which can be very important to all concerned in symbolic and existential as well as physical terms.

Ambiguous cases. Although for most seriously ill infants there will be either a clearly beneficial option or no beneficial therapeutic options at all, hard questions are raised by the smaller number for whom it is very difficult to assess whether the treatments available offer prospects of benefit—for example, a child with a debilitating and painful disease who might live with therapy, but only for a year or so, or a respirator-dependent premature infant whose long-term prognosis becomes bleaker with each passing day.

Much of the difficulty in these cases arises from factual uncertainty. For the many infants born prematurely, and sometimes for those with serious congenital defects, the only certainty is that without intensive care they are unlikely to survive; very little is known about how each individual will fare with treatment. Neonatology is too new a field to allow accurate predictions of which babies will survive and of the complications, handicaps, and potentials that the survivors might have.[83]

> that occur at birth. I personally foresee no medical solution to a cephalodymus or an anencephalic child. The first is a one-headed twin; the second, a child with virtually no functioning brain at all. In these cases the prognosis is an early and merciful death by natural causes. There are no so-called "heroic measures" possible and intervention would merely prolong the patient's process of dying. Some of nature's errors are extraordinary and frightening...but nature also has the kindness to take them away. For such infants, neither medicine nor law can be of any help. And neither medicine nor law should prolong these infants' process of dying.

Dr. C. Everett Koop, *Statement before Hearing on Handicapped Newborns, Subcomm. on Select Education Comm. on Education and Labor, U.S. House of Representatives* (Sept. 16, 1982).

[82] *See* pp. 91-94 *supra.*

[83] Uncertainty about the course is partly the consequence of the

The longer some of these babies survive, the more reliable the prognosis for the infant becomes and the clearer parents and professionals can be on whether further treatment is warranted or futile. Frequently, however, the prospect of long-term survival and the quality of that survival remain unclear for days, weeks, and months, during which time the infants may have an unpredictable and fluctuating course of advances and setbacks.

One way to avoid confronting anew the difficulties involved in evaluating each case is to adopt objective criteria to distinguish newborns who will receive life-sustaining treatment from those who will not. Such criteria would be justified if there were evidence that their adoption would lead to decisions more often being made correctly.

Strict treatment criteria proposed in the 1970s by a British physician for deciding which newborns with spina bifida[84]

rapidly expanding ability to save newborns who until recently could not have survived. Neonatal intensive care is a rapidly developing field and long-term follow-up on much of the most modern treatment is not yet available. Limited experience also compromises the ability to assess the effects—especially long-term physical and psychological effects—of medicine's effort to create a womb-like environment for the premature infant. *See* Albert R. Jonsen, *Justice and the Defective Newborn*, in Earl E. Shelp, ed., JUSTICE AND HEALTH CARE, D. Reidel Pub. Co., Boston (1981) at 95.

[84] John Lorber, *Early Results of Selective Treatment of Spina Bifida*

should receive treatment rested upon the location of the lesion (which influences degree of paralysis), the presence of hydrocephalus (fluid in the brain, which influences degree of retardation), and the likelihood of an infection. Some critics of this proposal argued with it on scientific grounds, such as objecting that long-term effects of spina bifida cannot be predicted with sufficient accuracy at birth.[85] Other critics, however, claimed this whole approach to ambiguous cases exhibited the "technical criteria fallacy."[86] They contended that an infant's future life—and hence the treatment decisions based on it—involves value considerations that are ignored when physicians focus solely on medical prognosis.[87]

> The decision [to treat or not] must also include evaluation of the meaning of existence with varying impairments. Great variation exists about these essentially evaluative elements among parents, physicians, and policy makers. It must be an open question whether these variations in evaluation are among the relevant factors to consider in making a treatment decision. When Lorber uses the phrase "contraindications to active therapy," he is medicalizing what are really value choices.[88]

Cystica, 4 Brit. Med. J. 201 (1973); John Lorber, *Results of Treatment of Myelomeningocele*, 13 Dev. Med. & Child Neurol. 279 (1971). *See also* Terrence F. Ackerman, *Meningomyelocele and Parental Commitment: A Policy Proposal Regarding Selection for Treatment*, 5 Man & Med. 291 (1980).

[85] John M. Freeman, *The Shortsighted Treatment of Myelomeningocele: A Long-Term Case Report*, 53 Pediatrics 311 (1974); Robert Reid, *Spina Bifida: The Fate of the Untreated*, 7 Hastings Ctr. Rep. 16 (Aug. 1977).

[86] Robert M. Veatch, *The Technical Criteria Fallacy*, 7 Hastings Ctr. Rep. 15, 16 (Aug. 1977).

[87] Courts, for example, sometimes automatically assume the priority of the value of a longer life. In the case of Kerri Ann McNulty, a Massachusetts probate judge ruled that corrective surgery had to be done on a month-old infant diagnosed as having congenital rubella, cataracts on both eyes, deafness, congenital heart failure, respiratory problems, and probable severe retardation. After reviewing the medical testimony, the court explicitly eschewed "quality of life" considerations, stating: "I am persuaded that the proposed cardiac surgery is not merely a life prolonging measure, but indeed is for the purpose of saving the life of this child, *regardless of the quality of that life*." In the Matter of Kerri Ann McNulty, No. 1960 (Probate Ct., Essex Co., Mass., Feb. 15, 1978).

[88] Veatch, *supra* note 86, at 15. *But see* Stuart F. Spicker and John R. Raye, *The Bearing of Prognosis on the Ethics of Medicine: Congenital Anomalies, the Social Context and the Law*, in Stuart F. Spicker, Joseph M. Healy, Jr., and H. Tristam Engelhardt, Jr., eds., The Law-Medicine Relation: A Philosophical Exploration, D. Reidel Pub. Co., Boston (1981) at 189, 202-05, 212.

The Commission agrees that such criteria necessarily include value considerations. Supposedly objective criteria such as birth weight limits or checklists for severity of spina bifida have not been shown to improve the quality of decision-making in ambiguous and complex cases. Instead, their use seems to remove the weight of responsibility too readily from those who should have to face the value questions—parents and health care providers.[89]

Furthermore, any set of standards, when honestly applied, leaves some difficult or uncertain cases. When a child's best interests are ambiguous, a decision based upon them will require prudent and discerning judgment. Defining the category of cases in a way that appropriately protects and encourages the exercise of parental judgment will sometimes be difficult. The procedures the Commission puts forward in the remainder of this chapter are intended to assist in differentiating between the infants whose interests are in fact uncertain and for whom surrogates' decisions (whether for or against therapy) should be honored, and those infants who would clearly benefit from a certain course of action, which, if not chosen by the parents and providers, ought to be authorized by persons acting for the state as *parens patriae*.

Policy Evaluation and Recommendations

The few systematic studies of decisionmaking about seriously ill newborns support the contentions of care professionals before the Commission and elsewhere that such decisionmaking usually adheres to the precepts outlined in this chapter.[90] As shown previously, however, problems of two kinds do occur: (1) parents receive outdated or incomplete information from their physicians and this limits their capacity to act as surrogate decisionmakers,[91] and (2) in what appears

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[89] Many have noted that diffusion of responsibility often acts to make no one feel responsible. *See, e.g.*, R. B. Zachary, *Commentary: On the Death of a Baby*, 7 J. Med. Ethics 5, 11 (1981).

[90] *See* notes 46-49 *supra*.

[91] Hein, *supra* note 74.

> When they [parents] begin to hear both points of view—sometimes it's only that there are excellent adoptive homes for such kids—that's often never raised—that changes the decision. Sometimes they just need to learn more about Down's. Parents have such horrible fantasies about it; it's mongolism and it's something monstrous, they think. This wider process is often nothing more exotic than bringing facts into the discussion.

Testimony of Dr. Norman Fost, transcript of 16th meeting of the President's Commission (Jan. 9, 1982) at 161.

to be a limited number of cases, inappropriate decisions are made without triggering a careful reevaluation.[92]

Improving Initial Decisions. The Commission believes that professional associations and health care institutions should help ensure that the best information is available and is used when decisions about life-sustaining treatment are made.[93] This is especially important in the cases of neonates because of both rapidly expanding medical capabilities and other efforts to maximize the potential of the disabled. Physicians should seek, and institutions might require, specialist consultations in such cases.

Where problems arise in communication between parents and nurses or physicians, institutions should provide responsive means to improve the communication and resolve the impasse. A high priority for care givers in this area should be the development of personal and team skills in communication and the enhancement of surrogates' capacities for effective decisionmaking.

Ensuring Appropriate Review. Although personal morality and compassion, high standards of professional ethics, and current laws and regulations ensure that the vast majority of decisions about seriously ill infants are made correctly and that incorrect decisions are redressed, occasionally actions are

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[92] Robertson, *supra* note 76. Perhaps the best-known case, and the only one in which there is an appellate court decision, is the one that has come to be known as the Infant Doe case, in which parents elected to forego treatment of their newborn child who had Down syndrome, tracheoesophageal atresia, and possibly additional anomalies. The course of nontreatment was one "medically recommended" way in which to proceed, according to the opinion of the trial court in an action brought by child welfare authorities on the complaint of some party other than either the physicians or the parents of the child. The trial court eventually sustained the parents' decision not to treat, *In re* Infant Doe, No. GU 8204-00 (Cir. Ct. Monroe County, Ind. April 12, 1982), *writ of mandamus dismissed sub nom.* State *ex rel.* Infant Doe v. Baker, No. 482 S 140 (Indiana Supreme Ct., May 27, 1982) (case mooted by child's death). Assessing this case is made difficult by the privacy concerns involved in judicial proceedings. *See* Steven R. Valentine, *Briefs Ordered Sealed in "Infant Doe" Appeal Case*, RIGHT TO LIFE NEWS, Nov. 24, 1982, at 8.

[93] You were asking if it is possible to do it [counsel parents of seriously ill newborns] without a team....I can't imagine doing it without a team, frankly, because there are so many different parts of each parent that need attending to in a decision that is the most excruciating one they will ever make, and no one professional discipline can do all of that.

Testimony of Carole Kennon, Social Worker, transcript of 16th meeting of the President's Commission (Jan 9, 1982) at 31. *See also* Hein, *supra* note 74.

taken without the consent of an infant's surrogate or tragically erroneous decisions are made by both physicians and surrogates. Judicial proceedings provide a possible means to handle these situations, although the Commission does not find them to be the best—nor even a very available and convenient—method.

Actions taken without a surrogate's consent are not readily susceptible to redress through the courts, since the parents are not likely to be in a position to evaluate—or even to detect—what is happening in their child's care if they are excluded from decisionmaking; furthermore, civil proceedings would be cumbersome, costly, and slow.[94] In many institutions, people concerned about erroneous decisions by both physicians and surrogates intervene only by complaining to public officials that child abuse or criminal homicide has occurred or may be about to occur. This very serious accusation usually requires that the complainant believes the evidence is sufficient to warrant legal action.

Furthermore, the adversarial atmosphere generated by this approach is unlikely to lead to infants receiving the most suitable care. The same problem arises with the regulations issued by the Department of Health and Human Services in the wake of the *Infant Doe* case[95] to prevent handicapped infants

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[94] I think we have...a real contrast in time-frame analysis between the medical and legal profession....When we talk about quick court decisions we are talking about 12 days. When I talk about quick, it means running down the stairs rather than taking an elevator....You have to understand when physicians want an answer they want it in 10 minutes. When lawyers produce an answer, they congratulate themselves for producing it in 10 days.

Testimony of Dr. Marianne Prout, transcript of 10th meeting of the President's Commission (June 4, 1981) at 35-36; Arnold Relman, *The Saikewicz Decision: A Medical Viewpoint*, 4 L. & MED. 233 (1978).

In addition to being ill-equipped to respond quickly enough to life-threatening situations, courts have been criticized for being unable to respond to the dynamic nature of decisionmaking necessary for medical treatment choices. *Compare* the statement of I. David Todres in Cynthia B. Wong and Judith P. Swazey, eds., DILEMMAS OF DYING: POLICIES AND PROCEDURES FOR DECISIONS NOT TO TREAT, G.K. Hall Med. Pub., Boston (1981) at 122-23 *with* Maine Medical Center v. Houle No. 74-145 (Super. Ct. Cumberland County, Me., Feb. 14, 1974) *reprinted in* Robert F. Weir, ed., ETHICAL ISSUES IN DEATH AND DYING, Columbia Univ. Press, New York (1977) at 185. *In re* Teague, No. 104-212-81886 (Cir. Ct. Baltimore, Md., filed Dec. 4, 1974) (child born with spina bifida died before action could be taken on the case.). *See* p. 159 *supra*.

[95] Office of the Secretary, Department of Health and Human Services, *Nondiscrimination on the Basis of Handicap*, 48 Federal Register 9630 (1983) (interim final rule modifying 45 C.F.R. § 84.61). *See also* Office

from being "discriminatorily denied food or other medical care."[96] Instead of adding further uncertainty to an already complex situation,[97] the Federal government would do better to encourage hospitals to improve their procedures for overseeing

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for Civil Rights, Department of Health and Human Services, *Discrimination Against the Handicapped by Withholding Treatment or Nourishment; Notice to Health Care Providers*, 47 Federal Register 26,017 (1982) (notice issued May 18, 1982, applying 45 C.F.R. Part 84 to health services for handicapped children), *reprinted in* Appendix H, pp. 467-68 *infra*.

Under the March 1983 notice, a warning must be posted in relevant places in hospitals that it is unlawful to exclude any "otherwise qualified handicapped individual" from the benefits of any Federally assisted program. A toll-free 24-hour "hotline" number is provided for anyone who knows of any handicapped infant who is being denied food or "customary medical care." Under the earlier notice, the Department reminded the nearly 7000 hospitals that receive Federal aid that existing HHS regulations apply § 504 of the Rehabilitation Act of 1973 to health services and treat Down Syndrome as a handicap within the meaning of § 504. Prior to 1982, § 504 had only been used once in the context of newborns with congenital anomalies. *See* Protection and Advocacy Agency of Hawaii v. Kapiolani Children's Hospital, Health and Human Services Doc. No. 09-79-3158 (1980), *cited in* Nancy Lee Jones, *Application of Section 504 of the Rehabilitation Act of 1973 to Handicapped Infants*, Congressional Research Service, Library of Congress, Washington (July 9, 1982).

[96] *Discrimination Against the Handicapped, supra* note 95, at 9630.

[97] Questions remain, for example, concerning such difficult matters as decisions regarding very low birth weight babies on the edge of viability, decisions for those with multiple serious congenital anomalies, and decisions for infants who are dying. Witnesses testifying before the Commission expressed concern that virtually every operative phrase of the DHHS directive needs amplification and would be subject to varieties of interpretation.

> There are two problems with Section 504: (1) it is not clear if or why a handicap can *never* be a justification for withholding treatment; and (2) the phrase "medically contraindicted" is ambiguous...the wording of this exemption is so vague that it is unintelligible. What is meant by a medical contraindication to treatment?....The language of Section 504 does not tell us *whether* it is permissible to withhold dialysis from a hydranencephalic child, or *why* it is impermissible to withhold intestinal surgery from a child with Down Syndrome.

Norman Fost, *Putting Hospitals on Notice*, 21 Hastings Ctr. Rep. 5 (Aug. 1982). *See also, Life Support Notice Attacked*, Am. Med. News, July 16, 1982 at 17 (response by American Academy of Pediatrics to the Section 504 directive).

Furthermore, the term "handicapped" is in no way limited in application to neonates. The impact of a regulation of this sort on the care of other patients could be substantially in conflict with this Report.

life-and-death decisions, especially regarding seriously ill newborns. Using financial sanctions against institutions to punish an "incorrect" decision in particular cases is likely to be ineffective and to lead to excessively detailed regulations that would involve government reimbursement officials in bedside decisionmaking. Furthermore, imposing such sanctions could unjustly penalize the hospital's other patients and professionals.

The Commission concludes that hospitals that care for seriously ill newborns should have explicit policies on decisionmaking procedures in cases involving life-sustaining treatment for these infants; accrediting bodies could appropriately require this. Such policies should provide for internal review whenever parents and the attending physician decide that life-sustaining therapy should be foregone. Other cases, such as when the physician and parents disagree, might well also be reviewed. The policy should allow for different types of review and be flexible enough to deal appropriately with the range of cases that could arise. Some cases may require only a medical consultation to confirm a diagnosis of an inevitably fatal condition, for example. In other cases, when the benefits of therapy are less clear, an "ethics committee" or similar body might be designated to review the decisionmaking process.[98] This approach would ensure that an individual or group whose function is to promote good decisionmaking reviews the most difficult cases. Cases included in this category should certainly encompass those in which a decision to forego life-sustaining therapy has been proposed because of a physical or mental handicap, as well as cases where a dispute has arisen among care givers and surrogates over the proper course of treatment.

Such a review could serve several functions and the review mechanism may vary accordingly. First, it can verify that the best information available is being used. Second, it can confirm the propriety of a decision that providers and parents have reached or confirm that the range of discretion accorded to the parents is appropriate. Third, it can resolve disputes among those involved in a decision, by improving communication and understanding among them and, if necessary, by siding with one party or another in a dispute. Finally, it can refer cases to public agencies (child protection services, probate courts, or prosecuting attorneys) when appropriate. Such a review mechanism has the potential both to guarantee a discussion of the issues with a concerned and disinterested "representative of the public" and to insulate these agonizing, tragic decisions from the glare of publicity and the distortions of public posturing that commonly attend court proceedings.

[98] *See* pp. 160-70 *supra*.

Insofar as possible, infants' lives should be sustained long enough to gather the best information and to permit expeditious review. When the parents and physician feel justified in acting without either or both of these conditions, as might happen with a rapidly deteriorating medical status, retrospective review should be undertaken.[99] Unlike turning to the courts for scrutiny of every case involving treatment of a seriously ill newborn, review of this limited category of cases would not seem likely to generate inappropriate social or financial costs.

In light of the lack of comprehensive information about decisionmaking practices and the fact that the Commission's recommendation is largely untried, the Commission encourages institutions, social scientists, and funding agencies to evaluate the effectiveness of such regularized review in order to improve its efficiency and efficacy and to refine the definition of the circumstances in which it is needed.

Long-Term Implications. The value society places on promoting the health and welfare of children has ramifications beyond neonatal intensive care units. When the decision is made to give seriously ill newborns life-sustaining treatment, an obligation is created to provide the continuing care that makes a reasonable range of life choices possible. A major conference on critically ill newborns concluded:

> The advocates of intensive care must become the advocates for development of humane continuing care and for sufficient funding of programs to support families whose children require special attention at home or in institutions. Neonatology cannot be developed in isolation from the continuing specialized care which, unfortunately, will be needed by some of the survivors of life-threatening neonatal disorders.[100]

Adoption and foster care should be available for parents unable to raise their seriously handicapped child.[101] To aid

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[99] Ensuring a retrospective review removes any incentive for hasty actions to avoid prospective review, a course that could be a disadvantage to at least some newborns. Retrospective review cannot change what happened to a particular child, but it can help ensure a high standard of decisionmaking practices in the institution and can censure seriously erroneous decisionmaking, both internally and by referral to the courts.

[100] Albert R. Jonsen *et al., Critical Issues in Newborn Intensive Care: A Conference Report and a Policy Proposal*, 55 PEDIATRICS 756, 764 (1975).

[101] As long as the state offers institutions that provide little more than storage space and "hay, oats, and water" for medical science's achievements, the law must err on the side of its strong presumption in favor of parental autonomy and family integrity. Thus for the state to do other than *either assume* full responsibility for the treatment, care, and nurture of such

parents, support that is responsive to the emotional and financial demands of handicapped persons and their families should be available. As a physician who has been pioneer in the treatment of infants and children recently commented, such support is an essential concomitant to a commitment to sustaining life.

> I'm very much involved in making sure that habilitation and rehabilitation of spina bifida individuals is advancing, because that's really the hope. If...I have preserved a thousand children who are going to sit in wheelchairs in nursing homes with normal intelligence....if that's what I've done, I've created a nightmare.[102]

Private organizations have made enormous contributions on behalf of the disabled; yet public funds may ultimately be needed so that these children, once rescued, are not then left to drown in a sea of indifference and unresponsiveness. Public support for effective voluntary organizations and governmental programs is the inescapable extension of society's deep interest in sustaining life in neonatal intensive care units. Furthermore, to the extent that society fails to ensure that seriously ill newborns have the opportunity for an adequate level of continuing care, its moral authority to intervene on behalf of a newborn whose life is in jeopardy is compromised.

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children *or honor* the parent's decision to consent to or refuse authorization for treatment would be but to pay cruel and oppressive lip service to notions of human dignity and the right to life.

Joseph Goldstein, *Medical Care for the Child at Risk: On State Supervision for the Child at Risk*, in Gaylin and Macklin, *supra* note 66, at 153.

[102] Dr. David McClone, Interview on *Sunday Morning* (transcript), CBS Network, Aug. 29, 1982, at 25.

Resuscitation Decisions for Hospitalized Patients

7

Origin and Scope of Resuscitation Efforts

Medical Capabilities. Resuscitation—the ability to rescue people from the brink of death by restoring life-giving heartbeat and breathing[1]—is one of modern medicine's most dramatic achievements.[2] The development of resuscitation techniques has been intimately connected with the refinement of medical instrumentation, the development of hospitals, and advances in anesthesia, surgery, and medical research generally.[3] Leading figures in the history of medicine have been at the

[1] Resuscitation is the revival of a living being from apparent death. Initially, medical efforts were aimed at restoring breathing (*e.g.*, in victims of asphyxiation). The concern of this chapter is limited, however, to the capability, developed over the past three decades, to reverse cessation of heartbeat (also termed cardiac arrest). Unless heartbeat is reestablished within minutes, damage to the brain becomes total and irreversible, spontaneous breathing cannot be recovered, and the patient is dead.

[2] Various means of resuscitation have long existed. The oldest account is probably the prophet Elisha's revival of the lifeless son of a Shunamite woman:

> And he went up, and lay upon the child, and put his mouth upon his mouth, and his eyes upon his eyes, and his hands upon his hands: and he stretched himself upon the child; and the flesh of the child waxed warm.

2 Kings 4:31-7 (New English).

[3] *See* D.K. Brooks, RESUSCITATION, William & Wilkins Co., Baltimore, Md. (1967).

forefront of these developments. Vesalius first described ventricular fibrillation[4] with its relationship to interrupted breathing, and he attempted intubation and artificial respiration with a reed inserted into a trachea.[5] In a pioneering 17th century work on circulation, William Harvey is credited with the first recorded direct manipulation of the heart (a pigeon's) as a resuscitation technique.[6] In 18th century Britain, John Hunter experimented with inserting the nozzle of a bellows into the trachea of a dog whose chest had been opened and found that spontaneous breathing could be restored after as much as ten minutes. Hunter was instrumental in establishing "receiving houses" along waterways for revival of nearly drowned sailors.[7] These buildings stocked resuscitation apparatus, including bellows and silver catheters for tracheotomies.[8]

An important round of advances in resuscitation techniques followed the development of anesthesia, first used in surgery in the 1840s.[9] Pioneering physicians using chloroform and ether soon found they had unsheathed a double-edged sword—anesthesia's remarkable ability to suspend consciousness carried a corresponding risk of cardiac arrest. Extensive animal experiments fostered the development of treatments for cardiac arrest during or following surgery. In 1898, French surgeons reported success in briefly restoring the heartbeat of an appendectomy patient when it stopped five days after surgery, an especially notable event because it was the first such attempt on a hospital ward.[10]

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[4] Ventricular fibrillation is a certain kind of ineffective heart motion that progresses rapidly to complete cardiac standstill unless treated but that is especially susceptible to correction by resuscitation.

[5] B.B. Milstein, CARDIAC ARREST AND RESUSCITATION, Lloyd-Luke Medical Books, London (1963) at 2; F.A. Willius and T.J. Dry, A HISTORY OF HEART AND CIRCULATION, W.B. Saunders Co., Philadelphia (1948).

[6] Carl E. Bartecchi, *Cardiopulmonary Resuscitation-An Element of Sophistication in the 18th Century*, 100 AM. HEART J. 580 (Oct. 1980).

[7] John Hunter, *Proposals for the Recovery of People Apparently Drowned*, 66 PHIL. TRANS. 412 (1776).

[8] I. McLellan, *Nineteenth Century Resuscitation Apparatus*, 36 ANESTHESIA 307 (1981).

[9] Logan Clendening, ed., SOURCE BOOK OF MEDICAL HISTORY, Dover Pub., New York (1942) at 355.

[10] Milstein, *supra* note 5, at 8; T. Tuffier and L. Hallion, *De la Compression rhymie du coeur dans la syncope cardique par embolie*, 24 BULL. SOC. CHIRURGIE PARIS 937 (1898).

Resuscitation of heart action became much more likely when pharmacologic and electric rhythm control interventions were developed in the 1940s.[11] It was discovered that adrenaline and procaine could restore heartbeat, and in 1947 the first instance of electric defibrillation of a heart was reported—a patient's heartbeat was restored after 70 minutes of ventricular fibrillation.[12]

In 1960, research demonstrated that circulation could be maintained in a patient without heartbeat by external cardiac massage.[13] Until this time, cardiac arrest had been treated by thoracotomy (surgically opening the chest) and direct massage. Emergency cardiac resuscitation[14] was first used mainly in recovery rooms, accompanied by the monitoring of electrocardiograms and arterial pressure. The procedure was fairly straightforward and was soon used in all parts of a hospital.[15]

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[11] H.D. Adams and L.V. Hand, *Twenty Minute Cardiac Arrest with Complete Recovery*, 118 J.A.M.A. 133 (1942); C.S. Beck, *Resuscitation for Cardiac Standstill and Ventricular Fibrillation Occurring During Operation*, 54 Am. J. Surg. 273 (1941).

[12] C.S. Beck, W.H. Pritchard, and H. Feil, *Ventricular Fibrillation of Long Duration Abolished by Electric Shock*, 135 J.A.M.A. 985 (1947). Electricity must have been thought useful in 1814, though specific cases are not reported. In the *Poetical Version of the Rules of the Humane Society for Recovering Drowned Persons*, published in May 1814 in The Cheap Magazine (see Figure 3, page 237), are these lines:

> The electric fluid, nature's purest fire,
> The soul-reviving vigor can inspire,
> Breathe through the frame a vivifying strife,
> And wake the torpid powers to sudden life.

Leonard Scherlis, *Poetical Version of the Rules of the Humane Society for Recovering Drowned Persons*, 9 Crit. Care Med. 430, 431 (1981).

[13] W.B. Kouwenhoven, J.R. Jude, and G.G. Knickerbocker, *Closed-chest Cardiac Massage*, 173 J.A.M.A. 1064 (1960). *See generally* Judith P. Swazey and Renée C. Fox, *The Clinical Moratorium: A Case Study of Mitral Value Surgery* in Paul A. Freund, Experimentation with Human Subjects, George Braziller, New York (1969) at 315; Lael Wertenbaker, To Mend the Heart, Viking Press, New York (1980).

[14] *See* American Heart Association and National Academy of Sciences/National Research Council, *Standards and Guidelines for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)*, 244 J.A.M.A. 453 (1980).

[15] This chapter focuses on resuscitation in hospitals, a setting that much more often allows for advance deliberation about undertaking resuscitation than does cardiac arrest at home or work. However, it did become clear in the 1960s that the lay public could be taught to perform emergency cardiopulmonary resuscitation with an acceptably low injury rate. Since then, training courses with practice manikins have been developed for groups such as lifeguards, police, firefighters, and ambulance personnel. For a treatment of the distinct but related issues concerning bystander-initiated resuscitation, see George J.

Over 15 years, cardiopulmonary resuscitation (CPR) using external compression has become routine in general hospital wards and emergency rooms and has given impetus to the newly developed specialized coronary and intensive care units.

Resuscitation after a cardiac arrest involves a series of steps directed toward sustaining adequate circulation of oxygenated blood to vital organs while heartbeat is restored.

> Efforts typically involve the use of cardiac massage or chest compression and the delivery of oxygen under compression through an endo-tracheal tube into the lungs. An electrocardiogram is connected to guide the resuscitation team....Various plastic tubes are usually inserted intravenously to supply medications or stimulants directly to the heart. Such medications can also be supplied by direct injection into the heart....A defibrillator may be used, applying electric shock to the heart to induce contractions. A pacemaker...may be fed through a large blood vessel directly to the heart's surface....These procedures, to be effective, must be initiated with a minimum of delay....Many of the procedures are obviously highly intrusive, and some are violent in nature. The defibrillator, for example, causes violent (and painful) muscle contractions which...may cause fracture of vertebrae or other bones.[16]

Though initially developed for otherwise healthy persons whose heartbeat and breathing failed following surgery or near-drowning, resuscitation procedures are now used with virtually everyone who has a cardiac arrest in a hospital. The initial success rate for in-hospital resuscitation is about one in three for all victims and two in three for patients hospitalized with irregularities of heart rhythm. Among patients who are successfully resuscitated, about one in three recovers enough to be discharged from the hospital eventually.[17] Especially

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Annas, *CPR: The Beat Goes On*, 12 HASTINGS CTR. REP. 24 (Aug. 1982); Mickey S. Eisenberg, Lawrence Bergner, and Alfred Hallstrom, *Cardiac Resuscitation in the Community,* 241 J.A.M.A. 1905 (1979); Robert G. Thompson, Alfred P. Hallstrom, and Leonard A. Cobb, *Bystander-Initiated Cardiopulmonary Resuscitation in the Management of Ventricular Fibrillation*, 90 ANNALS INT. MED. 737 (1979).

Sometimes "resuscitation" is used to cover a number of dramatic, emergency, life-sustaining interventions, including, for example, blood volume replacement. In this Report resuscitation is used only to refer to those efforts undertaken to restore heartbeat.

[16] *In re* Dinnerstein, 380 N.E.2d 134, 135-36 (Mass. App. 1978).

[17] W.A. Tweed *et al., Evaluation of Hospital-based Cardiac Resuscitation, 1973-1977*, 122 CAL. MED. ASSOC. J. 301 (1980). This rate is improved when fewer patients have resuscitation: at one center, a 56% successful resuscitation rate was reported when resuscitation was

when used on the general hospital population, long-term success is fairly rare. In the past decade, health care providers have begun to express concern that resuscitation is being used too frequently and sometimes on patients it harms rather than benefits.[18]

Special Characteristics of CPR. Cardiopulmonary resuscitation of hospitalized patients has certain special features that must be taken into account in both individual and institutional decisionmaking:

- Cardiac arrest occurs at some point in the dying process of every person, whatever the underlying cause of death. Hence the decision whether or not to attempt resuscitation is potentially relevant for all patients.
- Without a heartbeat, a person will die within a very few minutes (that is, heartbeat and breathing will both irreversibly cease).
- Once a patient's heart has stopped, any delay in resuscitation greatly reduces the efficacy of the effort. Hence a decision about whether to resuscitate ought to be made in advance.
- Although resuscitation grants a small number of patients both survival and recovery, attempts at it

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tried on only 30% of all in-hospital deaths. DeBard collected all cases in the literature and found 39% initial success and 17% discharge to home. Mark DeBard, *Cardiopulmonary Resuscitation: Analysis of Six Years' Experience and Review of the Literature*, 10 ANNALS EMERG. MED. 408 (1981). In contrast, Hershey and Fisher found only 3% success in a general hospital population where virtually all deaths were attended by resuscitation efforts. Charles O. Hershey and Linda Fisher, *Why Outcome of Cardiopulmonary Resuscitation in General Wards is Poor*, 1 LANCET 31 (1982). One careful prospective study found 4.9% long-term survivors of resuscitation efforts after cardiac arrest. Bernard Messert and Charles Quaglieri, *Cardiopulmonary Resuscitation Perspectives and Problems*, 1 LANCET 410, 411 (1976). One in 20 patients who have survived resuscitation has severe brain damage and about one in 4 has some serious and permanent injury. Clark Chipman *et al., Criteria for Cessation of CPR in the Emergency Department*, 10 ANNALS EMERG. MED. 11, 14 (1981).

[18] John Castagna, Herbert Shubin, and Max Harry Weil, *Cardiac Arrest in the Critically Ill Patient*, 2 HEART AND LUNG 847 (1973); I. Füsgen and J.D. Summa, *How Much Sense Is There to Resuscitate an Aged Person?*, 24 GERONTOLOGY 37 (1978); Thomas L. Petty, *Mechanical Last "Rights,"* 142 ARCH. INT. MED. 1442 (1982); (Editorial) *Cardiac Resuscitation in Hospital: More Restraint Needed?*, 1 LANCET 27 (1982); *Orders Not to Attempt Cardiac Resuscitation*, National Institutes of Health Clinical Center, Policy and Communications Bull. No. 82-4 (July 12, 1982).

usually fail; even when they reestablish heartbeat, they can cause substantial morbidity.[19]

- Clinical signs during resuscitation efforts do not reliably predict functional recovery of a patient.[20] Thus it is difficult to apply the sorts of adjustment and reconsideration that other interventions receive to a decision to resuscitate. Usually, the full range of efforts has to be applied until it is clear whether heartbeat can be restored.
- The conjectural nature of advance deliberations about whether or not to resuscitate may make the discussions difficult for the patient, family, and health care professionals.

Policies on Orders Not to Resuscitate. Pioneering policies on "No Code" orders ("code" being the shorthand term for the emergency summoning of a "resuscitation team" by the announcement of "Code Blue" over a hospital's public address system) or "DNR orders" (for "Do Not Resuscitate") were published by several hospitals in 1976.[21] The policies followed the recognition by professional organizations that non-resuscitation was appropriate when well-being would not be served by an attempt to reverse cardiac arrest. For example, the 1974 version of the "Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)" of the American Heart Association and the National Academy of Sciences states, "Cardiopulmonary resuscitation is not indicated in certain situations, such as in cases of terminal irreversible illness where death is not unexpected."[22]

A growing number of hospitals are now developing such policies,[23] while those with policies are already updating them,

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[19] *See, e.g.*, E. L. Nagel, *Complications of CPR*, 9 CRIT. CARE MED. 424 (1981).

[20] Chipman, *supra* note 17, at 14-16.

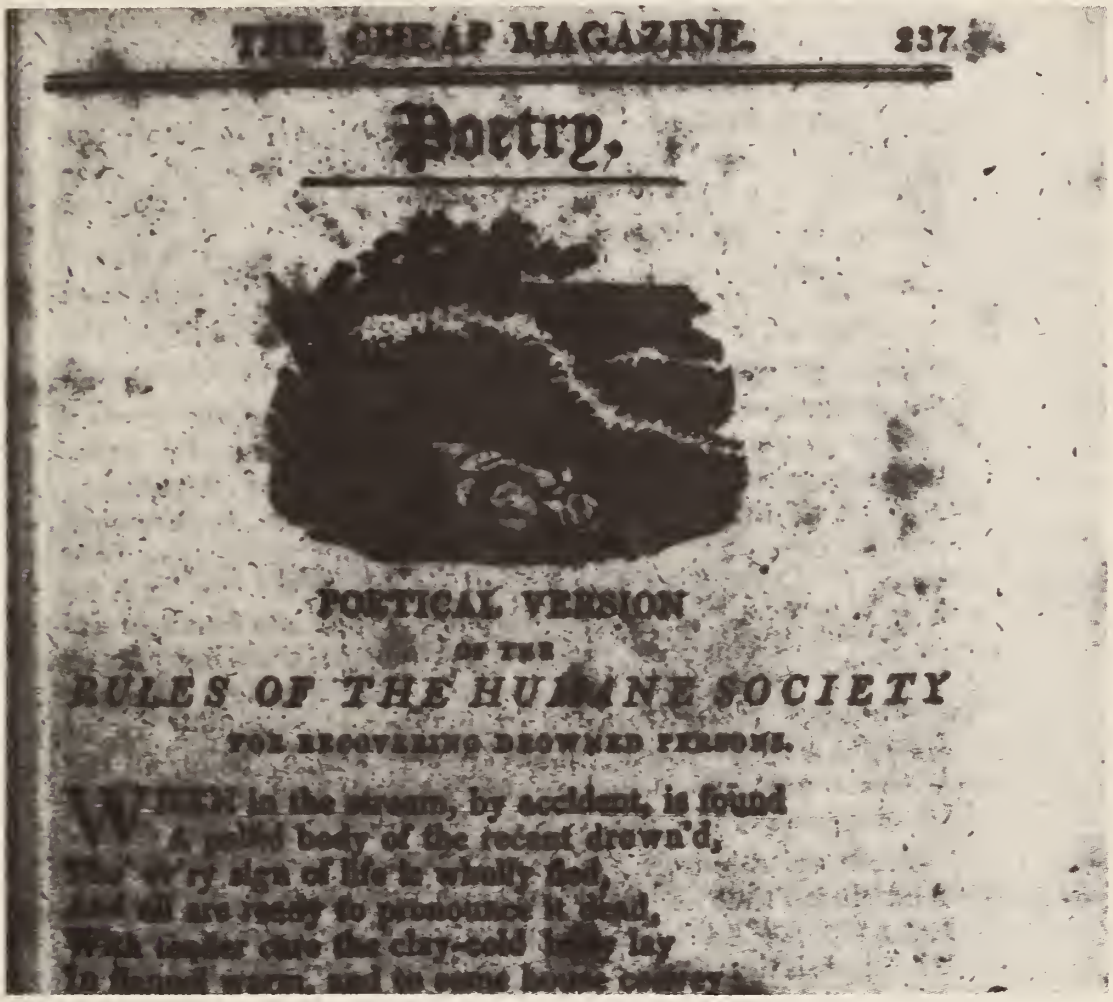
[21] Mitchell T. Rabkin, Gerald Gillerman, and Nancy R. Rice, *Orders Not to Resuscitate*, 295 NEW ENG. J. MED. 364 (1976); Optimum Care for Hopelessly Ill Patients: A Report of the Critical Care Committee of the Massachusetts General Hospital, 295 NEW ENG. J. MED. 362 (1976); M. Kirchner, *How to Go in Prolonging Life: One Hospital's System*, MED. ECON. (July 12, 1976); *See also* Francis P. Arena, Martin Perkin and Alan Turnbull, *Initial Experience with a "code-no code" Resuscitation System in Cancer Patients*, 8 CRIT. CARE MED. 733 (1980).

[22] National Conference Steering Committee, *Standards for Cardiopulmonary Resuscitation (CPR) and Emergency Cardiac Care (ECC)*, 227 J.A.M.A. 837, 864 (1974).

[23] The prevalence of written policies nationwide is not known. The Commission's experience, in organizing hearings and from letters it received, indicates that many hospitals are drafting policies, but that it is not uncommon, especially for community hospitals, not to have a written policy.

Figure 3: An 1814 Popularization of Resuscitation Procedures

Source: Leonard Scherlis, M.D., Poetical Version of the Rules of the Humane Society for Recovering Drowned Persons, 9 CRIT. CARE MED. *430 (1981).*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Poetry.

POETICAL VERSION

OF THE

RULES OF THE HUMANE SOCIETY

FOR RECOVERING DROWNED PERSONS.

especially to streamline procedures and to clarify that resuscitation is sometimes against good practice.[24] Three state medical societies—in Alabama, Minnesota, and New York—have promulgated brief guidelines to help establish the approved standard of care regarding DNR orders.[25] A Citizen's Committee in Los Angeles wrote guidelines for the county-run hospitals.[26] A 1982 survey of hospitals in San Francisco County and City found that policies had been written by all acute care hospitals but two—the ones run by the Veterans Administration and the Army.[27] The San Francisco Medical Society and the Bar Association of San Francisco collaborated to produce,

[24] *See, e.g., Guidelines: Orders Not to Resuscitate*, Beth Israel Hospital, Boston, Mass., March 31, 1981, *reprinted in* Appendix I, pp. 501-05 *infra*.

[25] *Reprinted in* Appendix I, pp. 497-500 *infra*.

[26] *Reprinted in* Appendix I, pp. 510-11 *infra*.

[27] Medical-Legal Interprofessional Committee, No Code Subcommittee, *Survey of No Code Guidelines in San Francisco Bay Area Hospitals* (1982).

with explanatory commentary, a model for developing each hospital's No-Code policy.[28] Representatives of the district attorney's office and the county coroner's office were involved in its development.

Legal Status. As would be expected with a practice so recently established, the writing of orders against resuscitation has received little attention in court. Even so, the few cases and opinions are surprisingly diverse, giving no clear direction as to a legal consensus. In the *Dinnerstein* Case, the intermediate appeals court of Massachusetts held that an order not to resuscitate a "patient in the terminal stages of an unremitting, incurable terminal illness" was appropriate and "peculiarly within the competence of the medical profession...in light of the patient's history and condition and the wishes of her family."[29] Yet news accounts in 1982 stated that a criminal investigation of a hospital in Queens was begun because the New York Attorney General's Office disapproved DNR orders being written for elderly, incompetent patients.[30]

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[28] *Reprinted in* Appendix I, pp. 494-97 *infra*.

[29] Shirley Dinnerstein was a 67-year old nursing home resident who suffered from Alzheimer's disease, a type of senile dementia. When her family and physician sought an action for declaratory relief to determine the legal status of a no-code order, she had progressed to the point where she was "in an essentially vegetative state," immobile, speechless, catheterized, and fed by a nasogastric tube. *In re* Dinnerstein, 380 N.E.2d 134, 135 (Mass. App. 1978). The *Dinnerstein* case came in the wake of the Massachusetts Supreme Court decision in *Saikewicz*, which some commentators had interpreted to require Probate Court approval of any decision to forego life-sustaining treatment of incompetent, terminally ill patients. Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417 (Mass. 1977).

But see, Hoyt v. St. Mary's Rehabilitation Center, D.C. File No. 774555, Hennepin County Minnesota District Court (Feb. 13, 1981) (findings of fact and order) slip op. at 3. In this case Jane Hoyt, a friend of 41-year-old Sharon Siebert, sought court review of Siebert's no code order. Mrs. Siebert suffered brain damage and required "total care," including nasogastric feeding. Her father consented to the order, but "understood that it meant Mrs. Siebert would not be placed on long term mechanical life support equipment; he did not understand that it meant that Mrs. Siebert would not be given brief emergency cardiopulmonary resuscitation." The court issued a restraining order to prevent the entering of a no-code order and substituted the friend instead of the father as guardian, noting, "the decision of the guardian was not made after due consideration...nor is there sufficient evidence that he sought to consider what Mrs. Seibert would have wanted had she been able to make the decision for herself." *See also* Jane Hoyt, *No Dr. Blue/Do Not Resuscitate*, 3 BIOETHICS Q. 128 (Summer 1981); Ronald E. Cranford and Mary S. Schneider, *Seibert Commentary: Medical-Legal Issues*, 3 BIOETHICS Q. 16 (Spring 1981).

[30] David Margolick, *Hospital Is Investigated on Life-Support Policy*, N.Y. TIMES, June 20, 1982, at A-34; Ronald Sullivan, *Hospitals Seek*

Not surprisingly, providers are uncertain about their liability under the law, and, in the words of one attorney who wrote to the Commission, "common sense is often subordinated to a hysterical reaction to the possibility of litigation."[31] A physician in a community hospital told the Commission:

> Older physicians are afraid of putting "do not resuscitate" down because they are afraid of being sued for making a wrong decision. The younger physicians are anxious to put a "do not resuscitate" down because they are afraid of being sued for making a wrong decision. The nurses will not act without a "do not resuscitate" because they are afraid of being sued.[32]

Even the authority of the courts regarding DNR orders is subject to divided opinion. In April 1982, Massachusetts held that the state's juvenile courts have authority to enter "no code" orders.[33] Three months later, the Attorney General of California wrote that probate courts in that state do not have such authority—contending, indeed, that a "no code" order cannot legally be written for an incompetent ward of the court in California.[34] Improvements in this situation probably depend on clarification of the underlying standard of socially accepted medical practices for decisions to forego resuscitation.[35]

Ethical Considerations

The Presumption Favoring Resuscitation. Resuscitation must be instituted immediately after cardiac arrest to have the best chance of success. Because its omission or delayed application is a grievous error when it should to have been

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Rules on Withholding Life-Support, N. Y. TIMES, Nov. 17, 1982, at B-3; *In re* Grand Jury Proceedings: People v. Doe, No. 333 (N.Y. Ct. App. June 18, 1982) (hospital may not assert physician-patient or social worker-client privilege or patients' right of privacy when facing valid grand jury *subpeona duces tecum*.)

[31] Stuart Showalter, Director, Division of Legal Services of the Catholic Health Association of the United States, quoted in a letter from John E. Curley, Jr., President of CHA, to the Commission (March 25, 1982). *See also*, "Few DNR orders are being written for incompetent patients in New York State at present, largely because district attorneys state that they consider such orders to be illegal and subject to criminal prosecution." Personal communication from Joel Glass, attorney with Ackerman, Salwen, and Glass, New York City, to Joanne Lynn (Jan. 10, 1983).

[32] Testimony of Dr. Albert Fine, transcript of 10th meeting of the President's Commission (June 4, 1981) at 95.

[33] Custody of a Minor, 434 N.E.2d 601 (Mass. 1982).

[34] 65 Ops. Cal. Att'y Gen. 4178 (1982), *reprinted in* Appendix I pp. 537-45 *infra*.

[35] *See e.g.*, Note, *No-Code Orders vs. Resuscitation: The Decision to Withhold Life-Prolonging Treatment from the Terminally Ill*, 26 WAYNE L. REV. 139 (1979).

used to attempt to save a life, most hospitals now provide for the rapid assembling of a team of skilled resuscitation professionals at the bedside of any patient whose heart stops.

When there has been no advance deliberation, this presumption in favor of resuscitation is justified. Although the concern a few years ago was about overtreatment, some health care professionals are now worried about unwarranted undertreatment—a weakening of the presumption in favor of resuscitation.[36] Very different presuppositions are involved when a physician feels a need to justify resuscitating as opposed to not resuscitating someone. In either case, however, the risks of an inappropriate decision with grave consequences for a patient are great if the issues are not properly addressed according to well-developed criteria. In order to avoid using resuscitation in circumstances when it would be appropriate to omit it, advance deliberation on the subject is indicated in most cases. As in all decisions in medicine, the basic issue should be what medical interventions, if any, serve a particular patient's interests and preferences best. When a person's interests or preferences cannot be known under the circumstances, a presumption to sustain the patient's life is warranted.

The Values at Stake. In considering the relative merits of a decision to resuscitate a patient, concerns arise from each of three value considerations—self-determination, well-being, and equity.[37]

Self-determination. Patient self-determination is especially important in decisions for or against resuscitation. Such decisions require that the value of extending life—usually for brief periods and commonly under conditions of substantial disability and suffering—be weighed against that of an earlier death. Different patients will have markedly different needs and concerns at the end of their lives; having a few more hours, days, or even weeks of life under constrained conditions can be much less important to some people than to others. In decisions concerning competent patients, therefore, first importance should be accorded to patient self-determination, and the patient's own decision should be accepted.

This great weight accorded to competent patients' self-determination means that attending physicians have a duty to ascertain patients' preferences,[38] which involves informing

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[36] *See, Doctor Sees Trend Not to Resuscitate*, WASH. POST, June 13, 1982, at A-4.

[37] *See* pp. 26-27 *supra*.

[38] Although the attending physician bears the responsibility, often others among the care giving professionals, religious advisors, or family members are in a good or better position to discuss the issues and convey the information. This is to be encouraged, but the physician is still obliged to see that it is done well.

each patient of the possible need for CPR and of the likely consequences (both beneficial and harmful) of either employing or foregoing it if the need arises.[39] When cardiac arrest is considered a significant possibility for a competent patient, a DNR order should be entered in the patient's hospital chart only after the patient has decided that is what he or she wants. When resuscitation is a remote prospect, however, the physician need not raise the issue unless CPR is known to be a subject of particular concern to the patient or to be against the patient's wishes. Some patients in the final stages of a terminal illness would experience needless harm in a detailed discussion of resuscitation procedures and consequences.[40] In such cases, the physician might discuss the situation in more general terms, seeking to elicit the individual's general preferences concerning "vigorous" or "extraordinary" efforts and inviting any further questions he or she may have.[41]

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[39] Contrary to the Commission's conclusions, some have contended that involving the patient is unnecessary:

> Consent of the patient is irrelevant because we are dealing with a situation in which there is no course of treatment for which to secure consent. This is different from the case in which there is a medically accepted course of treatment, but the patient does not wish to be subjected to this care.

William G. Ketterer, Senior Attorney, NIH, in a letter to James H. Erickson, Assistant Surgeon General and Joel M. Mangel, Deputy Assistant General Counsel for Public Health (April 8, 1977) at 6.

The Commission finds it necessary for the patient or surrogate to have given valid consent to any plan of treatment, whether involving omissions or actions, and rejects this claim. *See* pp. 66-73 and 126-31 *supra*.

[40] *See, e.g.*, "Such explanations to the patient, on the other hand, are thoughtless to the point of being cruel, unless the patient inquires, which he is extremely unlikely to do." Steven S. Spencer, *"Code" or "No Code": A Non Legal Opinion*, 300 NEW ENG. J. MED. 138, 139 (1979).

But see "The physician and family often underestimate the patient's ability to handle this issue and participate in the decision." Steven H. Miles, Ronald E. Cranford, and Alvin L. Schultz, *The Do-Not-Resuscitate Order in a Teaching Hospital*, 96 ANNALS INT. MED. 660, 661 (1982).

[41] Sometimes it seems cruel and unnecessary. Other times it is just difficult, in the midst of what is usually a very emotional and difficult time, to get around to the question of whether you want us pumping on your chest when you die....Having taken care of someone for some period of time has usually generated prior tacit, if not overt, understanding between the patient and me on these issues.

Michael Van Scoy-Mosher, *An Oncologist's Case for No-Code Orders*, in A. Edward Doudera and J. Douglas Peters, eds., LEGAL AND ETHICAL ASPECTS OF TREATING CRITICALLY AND TERMINALLY ILL PATIENTS, AUPHA Press, Ann Arbor, Mich. (1982) at 16; *see also* Ronald A. Carson and

Well-being. A second important ethical consideration is whether resuscitation will promote a patient's welfare. A physician's assessment of "benefit" to a patient incorporates both objective facts, based on the physician's evaluation of the patient's physical status before and following resuscitation, and subjective values, in considering whether resuscitation or non-resuscitation best serves the patient's own values and goals. In virtually all cases the attending physician is in a better position to evaluate the former, while a competent patient is best able to determine the relative value of alternative outcomes.

Even though decisions about resuscitation should recognize the importance of patients' self-determination it may sometimes be necessary to question patients' choices on the grounds of protecting well-being. First, a patient may be mistaken about the course of treatment that will actually achieve the end he or she desires. Even a competent patient may initially misunderstand the nature of alternative outcomes or their relationship to his or her values because of the complexity of the alternatives, the psychological barriers to understanding information, and so forth. Dissonance between the physician's and the patient's assessments of benefit point to the need for such steps as further discussion, reexamination of the patient's decisionmaking capacity, and reassessment of the physician's understanding of patient's goals and values; indeed, in some cases patients may even wish to evaluate their values and goals.

Second, decisions may have to be based on "well-being" because "self-determination" is not possible under the circumstances. Many patients for whom a decision not to resuscitate is indicated have inadequate decisional capacity, often due to their underlying illnesses. In these cases, providers and surrogates must assess whether resuscitation—like any other medical intervention—is or is not likely to benefit the patient. Of course, physicians face many of the same difficulties in deciding that patients do, and their attempts to assess "benefit" will not always lead to clear conclusions.

Equity. The Commission has concluded previously that "society has an ethical obligation to ensure equitable access to...an adequate level of care without excessive burdens."[42] Should resuscitation always be considered part of the "adequate level"? Resuscitation decisions are currently made with

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Mark Siegler, *Does "Doing Everything" Include CPR?,* 12 HASTINGS CTR. REP. 27 (Oct. 1982); John J. Paris, *Comfort Measures Only For "DNR" Orders*, 46 CONN. MED. 195 (April 1982).

[42] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, SECURING ACCESS TO HEALTH CARE, U.S. Government Printing Office, Washington (1983) at 4.

little regard to the costs incurred or to the manner in which costs are distributed, except when competent patients decide to include such considerations as a reflection of their own concern for family well-being or for distributional justice. The Commission heard from a number of people, however, who wondered if providers and others should consider whether the costs of resuscitation are warranted for those patients for whom survival is very unlikely and who would, in any case, suffer overwhelming disabilities and diseases.[43]

To determine whether cardiac resuscitation is a component of care that all hospitalized patients should have access to, the predicted value of this procedure would have to be compared with other medical procedures that generate comparable expenses and burdens. It is the Commission's sense that, at the moment, resuscitation efforts usually provide benefits that justify their cost, and thus resuscitation services generally should continue to be provided when desired by a patient or an appropriate surrogate. When, in a particular case, an attempt to resuscitate would clearly be against the patient's stated wishes or best interests, then the reason for not resuscitating does not arise from concerns for equitable use of societal resources, though it may incidentally help conserve them.

Of course, a more refined analysis of whether particular cases or categories of cases should be excluded under the

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[43] "[W]hether one month's additional cost of acute hospital care should or should not be incurred...is an important and relevant ingredient in the decisionmaking process...[W]e as a society must face the issue not of whether to preserve life but rather for how long." Letter from Joel May, Health Research and Educational Trust of New Jersey, to Joanne Lynn (May 11, 1982). "[T]he prolongation of life in hopeless situations must truly be viewed in the context of family resources and societal resources." Letter from Leo F. Greenawalt, President, Washington State Hospital Association, to Austin Ross, Vice-President, Virginia Mason Hospital, Seattle, WA (June 10, 1982). "Obviously, we must be very careful not to waste precious resources and money when it is to no avail." Letter from Dr. Ake Grenvik, Professor of Anesthesiology and Surgery, Univ. of Pittsburgh, to Joanne Lynn (March 30, 1982).

Proposals have been made that patients with advanced and irreversible diseases and organ system failures, including dementia, should not be offered resuscitation, principally because the expense and the necessary shifting of resources from other important uses are considered so disproportionate to the benefits. *E.g.*, in 1967 BBC-TV reported the following notice in a London hospital: "The following patients are not to be resuscitated: very elderly, over 65, malignant disease. Chronic chest disease. Chronic renal disease." In the controversy that ensued the physician who posted the notice received public support from a number of his colleagues. Louis Lasagna, *Physicians' Behavior Toward the Dying Patient*, in Orville Brim, Jr., *et al.*, eds., THE DYING PATIENT, Russell Sage Foundation, New York (1970) at 87.

Table 2:

Resuscitation (CPR) of Competent Patients—Physician's Assessment in Relation to Patient's Preference

Physician's Assessment	Patient Favors CPR*	No Preference	Patient Opposes CPR*
CPR Would Benefit Patient	Try CPR	Try CPR	Do not try CPR; review decision**
Benefit of CPR Unclear	Try CPR	Try CPR	Do not try CPR
CPR Would Not Benefit Patient	Try CPR; review decision**	Do not try CPR	Do not try CPR

* Based on an adequate understanding of the relevant information.

** Such a conflict calls for careful reexamination by both patient and physician. If neither the physician's assessment nor the patient's preference changes, then the competent patient's decision should be honored.

definition of "adequate care" might be attempted. A controversial step would be to attempt to eliminate resuscitations that, while advancing a patient's interests or in accord with a patient's preferences, sustained a very marginal existence at a very high cost.[44]

However, the negative consequences of trying to discern such categories in a workable way provide strong arguments against adopting such policies. Explicitly precluding resuscitation for some categories of patients would almost certainly be insensitive to their values, denigrating to their self-esteem, and distressing to health care professionals.[45] Also, the uncertainties over prognosis with resuscitation for each individual patient would make it very difficult to write clear and workable categories. It is unlikely that the costs incurred by marginally beneficial resuscitation are so substantial that their reduction should be a higher priority than the reduction of other well-documented kinds of wasteful or expensive and marginally beneficial care.[46]

Guidance for Decisionmaking

Competent Patients. When a competent patient's preference about resuscitation and a physician's assessment of its

[44] Resuscitation efforts themselves commonly cost over $1000 and usually entail substantial derivative costs in caring for the surviving patients who suffer side effects.

[45] *See* pp. 97-98 *supra*.

[46] *See* pp. 98-100 *supra*. *See also*, Securing Access to Health Care, *supra* note 42, at 185-90.

probable benefits coincide, the decision should simply be in accord with that agreement (see Table 2). When a physician is unclear whether resuscitation would benefit a patient but a competent patient has a clear preference on the subject, the moral claim of autonomy supports acting in accord with the patient's preference. Self-determination also supports honoring a previously competent patient's instructions.[47]

Some patients, although apparently competent, do not express a preference for one course over another. Such patients may not have reached a judgment in their own minds (saying, for example, merely, "whatever you think, Doc") or they may simply be unwilling to articulate a view one way or the other. Provided that the patient's unwillingness to declare a view at the moment does not reflect incompetence, the physician should not immediately ask family members to substitute their views for those of the patient, but should instead seek to involve family members in other useful ways (assuming that the patient does not object to their participation), comparable to the roles sometimes played by clergy, nurses, and other professionals. First, the family may be able to facilitate communication between the hospital staff and the patient, making sure that the issues to be addressed have been understood and helping to overcome any barriers to understanding. Second, they may be able to help the patient to make his or her preferences known to the care giving professionals. Ideally, these efforts will lead the patient to express a preference for or against resuscitation.

Of course, it is necessary to have some operative policy while a patient is being encouraged to make a choice, and patients should be informed about what that will be. Until the person expresses a clear preference, the policy in effect should be based on the physician's assessment of benefit to the patient; when it is unclear whether an attempt at CPR would be

[47] For a discussion of the rationale and procedures for prior directives *see* pp. 136-53 *supra*. The weight assigned to such written or oral instructions—in other words, the extent to which a presently *incompetent* patient is treating as expressing a *competent* preference through an advance directive—depends on the facts of each case.

If a patient while competent anticipated a later incompetence and medical condition, understood what should be entailed in a decision for or against resuscitation, and made firm and explicit statements regarding the decision, then those directives should be honored provided there is no reason to think that the patient's choice had changed or would have changed. Advance directives can be in the form of written instructions or of statements made to health care professionals, members of a patient's family, or others.

The physician will have to assess whether the patient adequately understood the ramifications of the choice and clearly stated his or her decision.

beneficial, there should be a presumption in favor of trying resuscitation.

When physicians and patients disagree about resuscitation, further discussion is warranted. Each can explain the basis of his or her position and why the other person's judgment seems unwarranted or mistaken. In some cases, consultation with experts may be helpful to resolve doubts about the facts of the case. Together, such steps often produce agreement.

Although disagreement in no way implies that a patient is incompetent, it will often be appropriate for the physician, and perhaps consultants or an advisory committee, to reexamine this issue if discussion does not lead to agreement between patient and physician—and also for the physician to reexamine his or her own thinking and to talk with advisors about it. The serious consequences of the patient's choice—which may include severe disability if resuscitation is tried or death if it is foregone—demand that this process be carried out with care. Once the adequacy of the patient's decisionmaking capacity is confirmed, then the patient's preference should be honored on grounds of self-determination, especially since the choice touches such important subjective values.

If a physician finds the course of action preferred by a competent patient to be medically or morally unacceptable and is unwilling to participate in carrying out the choice, he or she should help the patient find another physician. Indeed, such a change should be explored even when the physician is prepared to carry out the patient's wishes despite an initial disagreement if the difference of opinion created barriers to a good relationship.

Incompetent Patients. Decisionmaking for incompetent patients parallels that for competent ones except that when a physician or surrogate decisionmaker believes that resuscitation is not likely to benefit the patient, there are some additional constraints[48] (see Table 3). Whenever a surrogate and physician disagree, as when only one thinks that resuscitation is warranted, the case should receive careful review, initially through intrainstitutional consultation or ethics committees.[49] Urgent situations, however, or disagreements that are not resolved in this way should go to court. During such proceedings, resuscitation should be attempted if cardiac arrest occurs.

The review entailed will vary. When a physician feels that there is no benefit, a surrogate may either concur after additional consultations or may find another physician, espe-

[48] *See* Comment, *Medico-Legal Implications of "Orders Not to Resuscitate,"* 31 CATH. U. L. REV. 515, 535 (1982).
[49] *See* pp. 160-70 *supra.*

Table 3:

Resuscitation (CPR) of Incompetent Patients—Physician's Assessment in Relation to Surrogate's Preference

Physician's Assessment	Surrogate Favors CPR*	No Preference	Surrogate Opposes CPR*
CPR Would Benefit Patient	Try CPR	Try CPR	Try CPR until review of decision**
Benefit of CPR Unclear	Try CPR	Try CPR	Try CPR until review of decision**
CPR Would Not Benefit Patient	Try CPR until review of decision**	Try CPR until review of decision**	Do not try CPR

* Based on an adequate understanding of the relevant information.

** See pp. 246-48 *infra*.

cially if a consulting physician disagrees with the doctor who initially attended the patient. When a surrogate opposes resuscitation that a physician feels is beneficial, discussing the reasons in an impartial setting may uncover erroneous presuppositions, misunderstandings, or self-interested motives and allow for a resolution that is in the patient's best interests. When a surrogate is ambivalent, confirmation of the expected value of resuscitation by a consultant may be persuasive; continued ambivalence may signal the need for a new surrogate. The hospital will have to be able to ensure that helpful and effective responses are provided for these various situations.

If a patient has no surrogate and orders against resuscitation are contemplated, at least a *de facto* surrogate should be designated. When the physician feels that the decision against resuscitation is quite uncontroversial, a consultation with another physician, professional staff consensus, or agreement from an institutionally designated patient advocate can provide suitable confirmation of the initial judgment. Decisions like these are made commonly and should be within the scope of medical practice rather than requiring judicial proceedings. Decisions that are more complex or uncertain should occasion more formal intrainstitutional review and sometimes judicial appointment of a guardian.

Judicial Oversight. As made clear throughout this Report, the Commission believes that decisionmaking about life-sustaining care is rarely improved by resort to courts. Although

physicians might want court adjudication when they believe that a patient's decision against resuscitation is clearly and substantially against his or her interests, courts are unlikely to require people to submit to such an intrusive and painful therapy unless they conclude that the patient is incompetent.[50] Some form of review mechanism within a hospital is generally more appropriate and desirable for such disagreements. The courts are sometimes the appropriate forum for serious, intractable disagreements between a patient's surrogate and physician, however. When intrainstitutional procedures have not led to agreement in such cases, judges may well have to decide between two differing accounts of a patient's interests.

Institutional Policies

If DNR decisions always took place when there was time for deliberation and data gathering and only a few people were involved, little more would need to be said. However, potential rescuers often have limited personal knowledge of the patient and, once cardiac arrest occurs, there is no time for deliberation. Furthermore, too many people are involved to permit everyone to be brought into the decisionmaking process. In response to the special problems that attend resuscitation attempts,[51] formal and informal policies have been developed to govern decisionmaking and communication of decisions within institutions.[52] The Commission believes that institutional policymakers need to address three basic concerns.

The Need for Explicit Policies. Hospitals should have an explicit policy[53] on the practice of writing and implementing

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[50] *See* pp. 30-32, 39 *supra*. To stop recourse to the courts from becoming routine, the courts could decline DNR cases involving competent patients unless the circumstances were unusual. Particularly to be discouraged are cases in which physicians or hospitals desire court review of decisions that are actually uncontroversial, simply to shield themselves from liability.

[51] See pp. 235-36 *supra*.

[52] *See generally* Theodore R. LeBlang, *Does Your Hospital Have a Policy for No-Code Orders? Part 2*, 9 LEG. ASPECTS MED. PRACTICE 5, 6-7 (April 1981); No Code Subcommittee of the Medical-Legal Interprofessional Committee, sponsored by the San Francisco Medical Society and the Bar Association of San Francisco, *Final Report*, July 20, 1982, reprinted in Appendix I pp. 494-97 *infra*. Miles, Cranford, and Schultz, *supra* note 40; *No-Code Orders*, 7 L. REP. 1 (March 1982); Aileen McPheil *et al., One Hospital's Experience With a "Do No Resuscitate" Policy*, 125 CANADIAN MED. ASSOC. J. 830 (1980).

[53] Concerns about resuscitation practices are not, however, limited to the hospital settings. "All information available on CPR deals with hospital settings. I am concerned about long term care facilities because the population is different and I feel their age and condition preclude mandatory blanket CPR....The usual policy is to let the nurse

DNR orders.[54] In the absence of an established mechanism, decisionmaking might fail to meet the requirements of informed consent or the responsibility for making and carrying out the decision might be assigned to an inappropriate person.[55] Physicians should be allowed to decide to stop a resuscitation effort in progress, although the authority of inexperienced or untrained individuals to make such a decision should be limited. Moreover, without a deliberate process for reaching decisions about resuscitation, legitimate options may never receive the full consideration of patients, physicians, and other involved parties. Consultations with the nursing staff might well be required.[56]

Hospital policies should require appropriate communication with patients about the resuscitation decision. DNR policies should require that any such order be written in a patient's chart with sufficient documentation of the supporting reasons. Physicians may also need to review the order periodically, though changing a DNR order due to a revised assessment of its likelihood to benefit the patient will probably be rare.

The Need for Balanced Protection of Patients. Hospital policies should recognize that DNR orders can be justified by being in accord with a patient's competent choice or by serving the incompetent patient's well-being. Such policies can serve to remind staff that reflex resuscitation efforts applied to all patients not only denies people the ability to control the course of their own lives (a legal wrong) but also sometimes inflicts actual harm on individuals. At the same time, hospital policies on resuscitation should aim to protect the interests of incompetent patients (who are least likely to be able to protect

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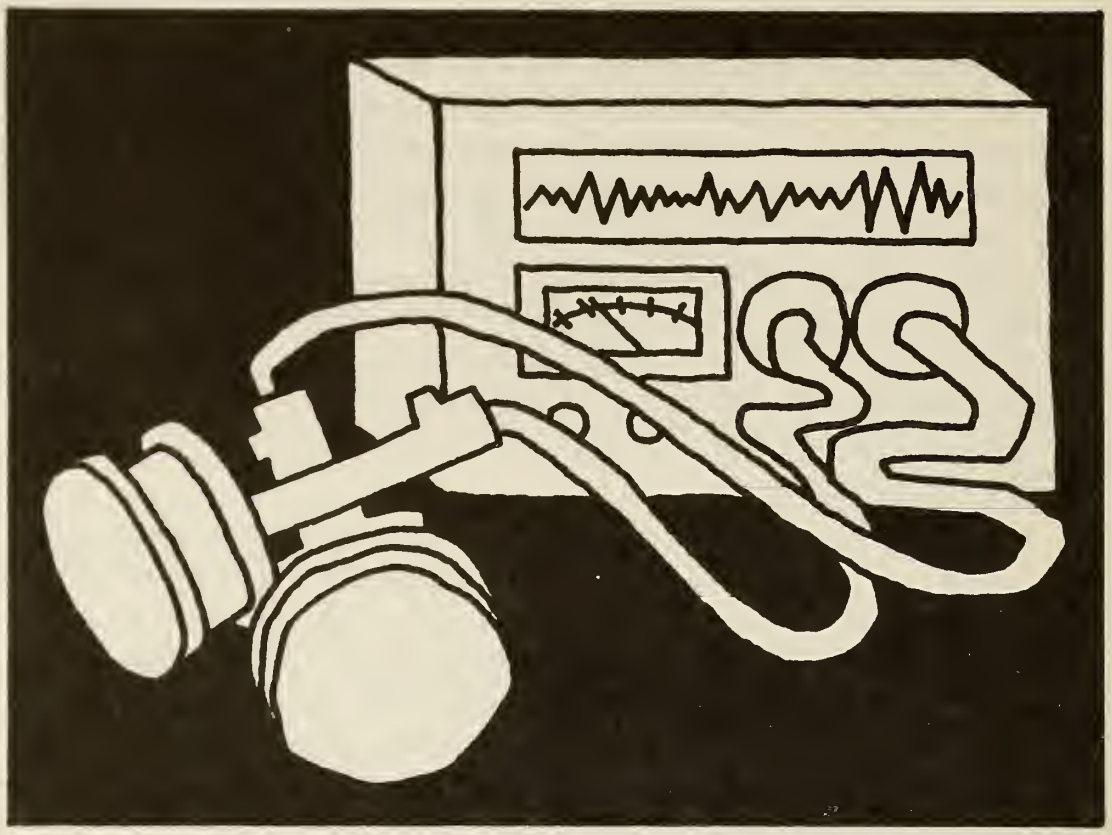
on the scene make a decision." A nurse quoted in Jane Greenlaw, *Orders Not to Resuscitate: Dilemma for Acute Care as Well as Long-Term Care Facilities*, 10 L., MED. & HEALTH CARE 29 (Feb. 1982).

[54] Since the principles governing decisionmaking about resuscitation are the same as for decisonmaking generally, such a policy might well include other decisions. Indeed, at Northwestern Memorial Hospital near Chicago, the policy covers all orders that preclude "the use of extraordinary or 'heroic' measures to maintain life." Reprinted in Appendix I pp. 511-13 *infra*. The policy at the University of Wisconsin's hospital covers decisionmaking generally. Reprinted in Appendix I pp. 513-17 *infra*.

[55] Mila Aroskar, Josephine M. Flaherty, and James M. Smith, *The Nurse and Orders Not to Resuscitate*, 7 HASTINGS CTR. REP. 27 (Aug. 1977); Leah Curtin, *CPR: Optimal Care vs. Maximal Treatment*, 10 SUPERVISOR NURSE 16 (Aug. 1979).

[56] "The physician must discuss his/her opinion and decision concerning both competence and DNR orders with the nursing staff from the outset and frequently thereafter." *Guidelines: Orders Not to Resuscitate*, Somerville Hospital, Mass., Memorandum #80-7, (Feb. 27, 1980), *reprinted in* Appendix I, pp. 507-10 *infra*.



themselves), by favoring resuscitation, for example, when the deliberations about a particular patient have not yet been completed. Indeed, for incompetent patients, the policy should make it clear that the presumption in favor of resuscitation can only be overcome by a finding that resuscitation offers a patient no significant overall benefit or that the patient would clearly not have wished to be resuscitated under the circumstances. Especially in treatment areas such as intensive and cardiac care units, where many patients are at risk for cardiac arrest, policies should try to reduce the number who are resuscitated without appropriate prior deliberation.

By encouraging prior deliberation, the policies can also reduce the need some now see for "partial resuscitation," in which less than a full effort to resuscitate the patient is made because the attending physician never made a clear decision or because it was thought important to placate or comfort family members or hospital staff.[57] Success at resuscitation is rare enough when all efforts are expended, so such limited efforts are usually doomed from the start. Thus, "partial codes" become a kind of dishonest effort that needs to be justified by

[57] [The use of partial codes] represents a tempting act of rationalization that is neither medically nor ethically sound. At best it is a waste of time and a failure to face reality and hard decisionmaking; at worst, it is an ethical fraud. I doubt that "partial codes" can be justified, but I see them frequently...

John Goldenring, Letter, 300 New Eng. J. Med. 1057, 1058 (1979).

reasons stronger than merely the providers' discomfort in discussing DNR decisions.[58]

Any DNR policy should ensure that the order not to resuscitate has no implications for any other treatment decision. Patients with DNR orders on their charts may still be quite appropriate candidates for all other vigorous care, including intensive care.[59] Thus, orders regarding supportive care that is to be provided should be written separately.

Finally, to respond to the conflict that professional staff feel and yet to protect patients' interests in preserving both personal choice and well-being, institutions may wish to provide guidelines for situations in which a patient with a DNR order suffers cardiac arrest as a result of a medical intervention.[60] Although the subject has not been well studied, patients whose cardiac arrest occurs under such circumstances may well have a better chance of successful resuscitation, since the arrest is more likely to have occurred in closely monitored settings and from fairly reversible causes.[61] Policies might

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[58] There are many forms of "codes": slow code, chemical code, partial code. In my opinion, there is a time and a place for a limited code. Recently, I took care of an Hassidic rabbi. Because Hassidic Jews are very uncomfortable with DNR orders or anything that might hasten death, such a course of action was not acceptable to him. We decided that it was reasonable to make some effort to resuscitate, but not necessarily all efforts. Setting such a limit on resuscitative efforts was acceptable to the family. In this case we decided that it would not be acceptable to intubate him nor to leave him on a respirator. So, there is a way of giving what I will call a partial code—some attempt at resuscitation, but not applying everything known to man.

Michael Van Scoy-Mosher, *supra* note 41, at 15 (citation omitted). *See also* Marc D. Basson, *Introduction: The Decision to Resuscitate—Slowly*, in Marc D. Basson, Rachel Lipson, and Doreen Ganos, eds., TROUBLING PROBLEMS IN MEDICAL ETHICS, Alan R. Liss, Inc., New York (1981) at 117; Paris, *supra* note 41.

[59] The no-resuscitation status is compatible with maximal and aggressive medical care, and does not imply that current treatment will be withdrawn or that additional therapy will not be initiated. Decisions as to the choice and level of treatment should be based on continued evaluation of clinical information and the patient's condition regardless of a do-not-resuscitate order.

Miles, Cranford, and Schultz, *supra* note 40, at 661. *But see* David Bar-Or, *The Do Not Resuscitate Order* (Letter), 97 ANNALS INT. MED. 280 (1982); George Spelvin (pseudonym), *Should a 'No-Code' Be a Death Sentence?*, MED. WORLD NEWS 64 (April 27, 1981).

[60] *See* pp. 94-95 *supra*.

[61] In one series of 48 cases, two patients whose cardiac arrests resulted directly from biomedical procedures survived resuscitation to go home. Arena, Perlin, and Turnbull, *supra* note 21, at 734. In

require specific discussion of this issue in certain settings or acknowledge that sometimes the DNR order is justifiably overridden.

The Need for Internal Advice and Review. Hospital policy should provide for appropriate resolution of disagreements on resuscitation decisions. Intrainstitutional review of decisions that raise persistent disagreements has been shown to be very effective in some institutions, both for clarifying the issues in a case and for achieving compassionate and responsive resolution of the issues.[62]

Hospital staff should not be forced to undertake an action they regard as unethical. All staff should have access to the review mechanism for advice and for clarifying the issues. If that proves unsatisfactory, every effort should be made to have other staff from within the institution care for the patient. Barring that, if the person's medical condition allows it, transfer to another institution may be appropriate. Hospital staff should try, however, to avoid becoming so inflexible that they are unable to respond comfortably to appropriate orders, whether for or against resuscitation. Hospitals have a responsibility in staff education and recruitment to provide sufficient staff resources and flexibility.

Cases should be brought to court when it is necessary to decide whether a patient is competent to make a decision not to be resuscitated or, if not competent, which decision serves the patient's interests. Very few, if any, cases should be brought to court solely to protect the hospital from the unlikely prospect of liability.

Policy Implications

Law. If hospitals ensure that decisionmaking practices are reasonable and that internal review and advice are readily available, decisions concerning resuscitation will seldom need to come before courts. Adequate protection of the interests of incompetent patients should probably be achieved by holding the physician and institutional officials responsible for obtaining appropriate review when a surrogate's decision seems erroneous and for referring to court those disputes that remain unresolved after these internal processes. Also, each state should have some court with clear jurisidiction over these

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particular, policies should encourage consideration of this potential dilemma when especially risky procedures are being discussed with a patient who otherwise would have a DNR order.

[62] Comment, *Medico-Legal Implications of "Orders Not to Resuscitate," supra* note 48, at 518 n.9; Testimony of Dr. Mitchell Rabkin, transcript of 10th meeting of the President's Commission (June 4, 1981) at 65-69.

cases and with power to decide that certain patients' conditions might warrant DNR orders.

In states and localities in which prosecutors have indicated that they do not condone DNR orders and that they might bring criminal charges against physicians or hospitals that use such policies,[63] the public, as well as health care professionals and institutions, should defend the practice and make it clear that nonresuscitation is being used thoughtfully and correctly.

Federal Involvement. The Federal government is a significant financer and provider of health care. In its role as funder the government must be careful not to link reimbursement rates to resuscitation status. Such linkage has arisen once in the response of providers to a directive from the California State Health Department. This "Field Instruction Notice" stated: "a terminally ill patient with a 'no code' status and those care needs limited to making the person as comfortable as possible and free of pain, while preserving that person's personal dignity to the extent possible, would not meet the criteria for acute hospitalization." The response of California practitioners to what amounts to an automatic review of the appropriate Medi-Cal reimbursement level (which was very likely to be downgraded from hospital level to skilled nursing facility) was apparently to issue few DNR orders on Medi-Cal patients in the hospital. This was an unfortunate and foreseeable effect of what is, on its face, a quite reasonable Medi-Cal policy and illustrates why such review should use other, more fixed, indices of patients' needs.[64] The existence or nonexistence of a DNR order does not in itself signify whether other care is appropriate or inappropriate; intensive efforts to support a seriously ill patient are not rendered inappropriate simply because attempts to revive the patient would be unwarranted in the event of a cardiac arrest.

As providers of health care, the various Federal agencies should develop policies and practices in accord with those outlined above. For the Veterans Administration (VA), the closest to an official policy statement on DNR orders is found in a Chief Medical Director's letter[65] of November 20, 1979, that focuses on the fact that a "no code" order can violate the conscience of a nurse or other provider who was not a party to

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[63] *See* notes 30, 31, and 34 *supra.*

[64] *Level of Care Determination on Acute Care Patients, and How it Relates to a Terminal Patient with a "No-Code" status*, memorandum, California Dept. of Health Services, *reprinted in* Appendix I, pp. 535-36 *infra.*

[65] Letter from James C. Crutcher, VA Chief Medical Director, to Directors, VA Medical and Regional Office Centers, Domiciliary, Outpatient Clinics, and Regional Offices with Outpatient Clinics Regarding "No Code" and Other Similar Orders (Nov. 20, 1979), *reprinted in* Appendix I, pp. 518-19 *infra.*

the original decision and who may disagree with it. The response was to leave the decision to the judgment of "the health care provider caring for the patient at the time of cardiopulmonary arrest."[66] To permit that provider to make a sound judgment, the letter encourages adequate documentation in progress notes of "the diagnosis, the prognosis, the patient's wishes (when known), the wishes of the family members and the recommendations of the attending staff (not resident) physician."[67] Some VA hospitals do not follow this policy; sometimes different services within a given hospital follow differing policies; and sometimes a VA hospital follows this policy while a neighboring hospital run by medical school that the VA hospital is closely affiliated with has a policy more in line with the one recommended in this chapter. The Commission recommends that the VA revise its policy in line with the Commission's analysis in this Report or encourage individual hospitals to do so.[68] At the very least the policy should be adjusted to ensure that patients' interests and preferences become its central focus.

Medical treatment facilities operated by the Department of Defense currently address the DNR issue in quite disparate ways. There seems to have been a general reluctance to allow DNR orders, perhaps stemming from such policies as the Army Surgeon General's letter[69] of December 13, 1977, which seems to say that, except when mandated under natural death acts, orders may never by given not to resuscitate a patient. Some individual military hospitals are in the process of writing policies.[70] Some Navy and Army physicians advocate revision of the overall policies to ensure that DNR orders in military facilities are congruent with good ethical practice and law.[71] The Commission endorses such a revision and the introduction of clear policy that encourages correct use of DNR orders and of CPR.

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[66] *Id.* at 519.

[67] *Id.*

[68] Although involving discontinuation of a respirator rather than CPR, the VA was recently sued for refusing to discontinue a life-sustaining treatment. Foster v. Tourlettotte, No. CV81-5046 (S.D. Cal. May 27, 1982); Dorothy Townsend, *Court Upholds Man's Plea for Cutoff Life Support*, L. A. Times, Oct. 24, 1981, at A-1.

[69] *See* Appendix I, pp. 520-22 *infra*.

[70] For example, the National Naval Medical Center in Bethesda, Md., has written a policy that is substantially in conformity with the recommendations in this chapter.

[71] *See, e.g.*, Letter from Dr. James G. Zimmerly, J.D., M.P.H., Col, MC, USA, to LTG Berhard T. Mittemeyer, MC, USA, *Termination of Life Support and Entering of No-Code Orders* (April 1, 1982), *reprinted in* Appendix I, pp. 522-29 *infra*.

The Public Health Service, in its direct provision of health services at the Clinical Center of the National Institute of Health, has adopted a brief and quite acceptable policy.[72] There seems to be no overall policy regarding other aspects of Public Health Service health care delivery, though practices may well be regulated at a local level.

Hospital Accreditation. Much of medical practice is governed by independent and private organizations, which, like the government, bear a responsibility to encourage sound decisions regarding resuscitation. Organizations that accredit health care institutions do not now mandate any policy or education on the subject of resuscitation beyond the requirement of the Joint Commission on the Accreditation of Hospitals that special care unit staff know the medical procedures involved and that all orders about patient care be written ones.[73] At the least, in order to be accredited hospitals should be required to have a general policy regarding resuscitation—preferably one that addresses the three basic needs discussed in this chapter.

Professional Education. Similarly, physicians and hospital staff should be educated concerning resuscitation decisions. The policymakers and organizations responsible for medical school accreditation, standardized examinations for medical students, physician and nurse licensure, and physician specialty certification should adopt appropriate training and education requirements.

[72] Policy and Communications Bull. No. 82-4, *Orders Not to Attempt Cardiac Resuscitation*, National Institutes of Health Clinical Center, (July 12, 1982), *reprinted in* Appendix I, pp. 519-20 *infra*.

[73] Joint Commission on Accreditation of Hospitals, ACCREDITATION MANUAL FOR HOSPITALS, Chicago (1981 ed.) at 184.

Deciding to Forego Life-Sustaining Treatment Appendices

The Commission's Process

This Report on the ethical, legal, and practical aspects of decisions to forego life-sustaining treatment draws on work done by the Commission in several areas over the past three years, along with testimony and public comment on the subject at several public hearings and meetings. The conclusions of the Commission's reports on *Making Health Care Decisions* and on *Securing Access to Health Care*, in addition to considerations highlighted in the Commission's report *Defining Death*, were considered and applied to this Report. The topic of deciding about life-sustaining treatment was before the Commission at 12 meetings, and testimony and documentary materials were presented by physicians, nurses, social workers, patients and family members, philosophers, theologians, and lawyers by invitation and as witnesses during the public comment periods. The Commission's work was greatly assisted by many letters of advice and critiques of drafts from concerned professionals and members of the public. Especially detailed and helpful critiques of each draft were provided by Dr. Ake Grenvik, of the University of Pittsburgh, and Dr. Ronald Cranford, of the Hennepin County Medical Center in Minneapolis.

Former Commissioners

These members served on the Commission while this study was being conducted; their terms of service, which were completed before the Report was approved, are indicated in parentheses.

Renée C. Fox (July 1979-Feb. 1982)

Mario Garcia-Palmieri (July 1979-Aug. 1982)

Frances K. Graham (May 1980-Jan. 1982)

Albert R. Jonsen (July 1979-Aug. 1982)

Patricia A. King (July 1979-May 1980)

Mathilde Krim (July 1979-Oct. 1981)

Donald N. Medearis (July 1979-Feb. 1982)

Anne A. Scitovsky (July 1979-Aug. 1982)

Carolyn A. Williams (Sept. 1980-Aug. 1982)

Commission Hearings

April 9, 1981

On April 9, 1981, the Commission held a hearing in Miami, Florida, with the Chairman presiding. A major focus of the session was the case of Abe (Al) Perlmutter, a 71-year-old Floridian who was striken with amyotrophic lateral sclerosis (Lou Gehrig's Disease), a progressive neurologic disease that causes muscle deterioration, eventuating in death. Perlmutter was last hospitalized in May of 1978 when he needed an artificial respirator to support his breathing. When his attending physician declined to follow his wish that the respirator be disconnected, Perlmutter began a legal action, which eventually stretched out over two years. He died five months after the initial court proceeding, 41 hours after his respirator was removed pursuant to an order of the Florida Court of Appeals; the courts continued to rule on the legal issues even after Perlmutter had died.

The first witness before the Commission was David Hoines, the attorney who represented Perlmutter before the trial, appellate, and Florida Supreme Courts. Hoines explained that he had advised the Perlmutter family that they and the hospital staff could possibly be prosecuted for a second-degree felony under a Florida statute against "assisting self-murder" if they disconnected Al Perlmutter's respirator. In answer to questions, he stated that there were no Florida cases of which he knew in which family members or others had been prosecuted under comparable circumstances. (This conclusion was confirmed by the other attorneys who testified before the Commission during this hearing on the *Perlmutter* case.) Hoines stressed that Perlmutter did not seek to die, but preferred death to continuing to live in his debilitated condition, and that he was steadfast in this wish.

Dr. Marshall J. Brumer, a pulmonary specialist and one of Perlmutter's attending physicians, testified that he resisted the patient's decision to forego treatment because he believes that physicians have a duty to preserve life. He also believed that Perlmutter was depressed due to the death of his wife shortly after he was admitted to the hospital; his mood and outlook vacillated, and at times Perlmutter spoke of his hope for

improvement. Dr. Brumer told the Commission that in all his years of practice he had never had a patient who held to his or her wish to cease treatment consistently enough to convince Dr. Brumer. He stressed that Perlmutter had always been free to sign out of the hospital "against medical advice" (and that the doctor would have helped make provision for respirator care at home). In his experience sick and depressed patients often expressed wishes to die, but he had never encountered a patient whose wish was steadfast or whose interests would be served by physician compliance. Dr. Brumer also explained the effects that the threat of legal liability had on his decisions.

Judge John G. Ferris, trial judge of Broward County, Florida, told the Commission of his decisionmaking process, which upheld Perlmutter's right to refuse treatment. Judge Ferris said his opinion did not *order* Dr. Brumer to remove the respirator, but rather gave Perlmutter the *option* to have the respirator removed, based on his constitutional right of privacy.

Charles Musgrove, who handled the appeal for the state, noted that the law in Florida was unclear, given the dearth of case law and the silence of the legislature. He maintained the need for further clarification of patients' rights in regard to decisions to forego life-sustaining therapy. Judge Patti Englander, who had been with the State Attorney's office in Broward County during the Perlmutter litigation, explained that this was the reason for continuing the appeal after Perlmutter died. She testified further that she had urged the Florida Supreme Court (successfully) to interpret the constitutional right to privacy narrowly: it should be applied only to those, like Al Perlmutter, who, as competent, terminally ill adults, desire removal of extraordinary therapy and who have only adult children who agree with the decision.

The Commission then turned to a discussion of autonomy and institutional options in the context of terminally ill patients. Testimony was heard from Reverend Ronal Mudd, a hospital chaplain who has counseled dying patients for 16 years and who is one of the founders of the Methodist Hospice in Jacksonville, Florida. Rev. Mudd had recently been diagnosed as having cancer and noted that research shows that doctors, nurses, and clergy tend to spend less time with patients they know to be dying than with other patients. He suggested that the Commission ought to explore more fully the hospice concept of palliative and comprehensive care for the dying.

Frank Repensek, Director of the Guardianship Program for the Elderly of Dade County, spoke on decisionmaking for incompetent patients. Repensek's staff of social workers act as guardians for the elderly, a large number of whom are referred by area hospitals when patients are not in a condition to make

an informed choice about treatment. He noted that the laws of guardianship are clearer concerning property than concerning persons.

Monsignor Bryan Walsh testified as Director of the Catholic Charities, Archdiocese of Miami, on the attitude of the Church. He explained that, while rejecting "mercy killing" and suicide as universally wrong, the Church sanctions the omission of medical procedures considered to be extraordinary or "disproportionate." These views were reiterated in the Vatican Declaration on Euthanasia of June 26, 1980. Monsignor Walsh cited the recently adopted policy and procedure statement of the Jackson Memorial Hospital as an example of how such decisions are made and noted that the guidelines were designed to alleviate uncertainty on the part of hospital staff regarding its rights and duties.

Mary Narvaez, a nurse who practices in the oncology unit of the University of Miami Hospital, discussed how nurses often find themselves torn among allegiances to the patient, the family, and the doctor. She concluded that education in management of dying patients might be useful. Dr. Peter Mansell, an Associate Professor of Medical Oncology at the University of Miami Comprehensive Cancer Center, described the tendency, particularly among American doctors, to exhaust all therapies for patients who are dying of malignant diseases. He expressed doubt that broad rules, regulations, or legislation could be drafted that would apply to the wide variety of unique cases; he also warned against an automatic assumption that spouses or close family members have the patient's "best interest" at heart.

Dr. Warren Lindau, a cardiologist in private practice who is President of the Dade County Medical Society, testified that he routinely encounters problems in decisionmaking about ending life-sustaining treatment. He emphasized the difficulty of adequate communication in the face of depression and confusion, the difficulty of ascertaining the motives of family members, and the extraordinary costs of the medical interventions involved. Vynette McGlawn, administrator of the Jackson Heights Nursing Home in Miami, discussed the plight of the elderly patient, particularly the problems of finding appropriate surrogates for incompetent patients and of making good decisions regarding both life-sustaining treatment and routine medical care through some other means.

The Commission also heard testimony on the subject of legislation at the state level that would authorize a "terminally ill patient" to execute a document directing physicians to limit treatment should a patient become so debilitated as to be unable to continue to participate in decisionmaking about his or her care. A letter from Florida State Senator Paul B. Steinberg, sponsor of the "Directive of Natural Death Act,"

was read into the record. Dr. James Farr, pastor of the Synder Memorial United Methodist Church of Jacksonville, Florida, spoke in favor of legislation to guarantee the right to refuse life-prolonging treatment, based on the doctrine of informed consent and the constitutional right of privacy. He also spoke of the need to immunize physicians and families from criminal and civil liability and the need to clarify rights with regard to insurance coverage. Dr. Farr expressed some reservations about "living will" legislation, saying that it must be drafted to protect vulnerable populations, especially the aged and severely retarded.

Thomas Horkan, an attorney testifying on behalf of the Florida Catholic Conference, opposed any legislation concerning the rights of dying patients. He said that decisions to omit or withdraw extraordinary treatment are best made by patients or families in concert with physicians and clergy. Reverend Donald McKinney, board member and founder of the national organization Concern for Dying, told the Commissioners that his organization has concluded that legislation is unnecessary and perhaps even an impediment to honoring patients' wishes. As an alternative to legislation, he suggested that educational efforts be strengthened. His organization does, however, endorse the concept of the "living will." Sidney Rosoff, a New York attorney who is President of the Society for the Right to Die, told the Commissioners of the efforts of his organization to promote living will legislation, because his group believes that legislation is preferable to litigation.

Moving from the realm of legal rules, the Commission heard from Philippa Foot, Professor of Philosophy at UCLA and Senior Research Fellow at Somerville College, Oxford. To summarize her views, she provided the Commission with a "flow diagram" that listed pertinent questions in a fashion that permitted the appropriate questions to be asked of each presented case. Professor Foot stressed that these questions only help to sort out cases and do not provide any answers.

During the time set aside for public comment, the Commission heard from Dr. Walter Sackett, a pediatrician in private practice and a former Florida State Representative who had introduced the nation's first "death with dignity" bill more than a decade earlier. He encouraged the Commission to examine the full range of situations when foregoing therapy is appropriate. George Wallace-Barnhill, Chairman of the Legal/Ethical Issues Committee of the Society for Critical Care Medicine, commented on the difficulty that these decisions pose for emergency room and critical care specialists. Carol Davis, a physical therapist, encouraged the Commission to develop some substantial guidelines on who should forego life-sustaining treatment. Jackie Matuseski, a social worker and adminis-

trator of a hospice program, advocated the provision of true choices for all patients, especially for dying patients.

June 4, 1981

The Commission next took up this subject during its hearings in Boston, which were presided over by the Chairman, because a remarkable number of noteworthy cases involving the termination of life-sustaining treatment for incompetent patients have come before the Massachusetts courts. Their decisions have sparked considerable debate within the medical and legal communities over the role of courts in the treatment or nontreatment of dying patients.

Dr. Marianne Prout, Director of the Division of Oncology at Boston University Hospital, described her work with terminally ill patients, noting that fluctuations in competence are quite common. She explained that difficulties and delays in obtaining guardians for incompetent patients have led some physicians to continue life-sustaining treatment for what she feels is an unjustified period.

Leonard Glantz, Assistant Professor of Law and Medicine at Boston University School of Medicine, summarized the state of the law in Massachusetts, discussing the *Saikewicz* case, the role of the "substituted judgment" test, and the frequency with which recourse to courts must be sought. Dr. Arnold Relman, Editor of the *New England Journal of Medicine*, endorsed the social tradition of physicians and families deciding together about care for patients of diminished capacity. Professor Jonathan Brant, of the New England College of Law in Boston, countered by noting that physicians and families may have interests that conflict with those of incompetent patients. He urged court attention for decisions involving life-sustaining treatment for dependent people.

The discussion then turned to questions of how institutional policies can be framed to encourage appropriate care of terminally ill patients. Dr. Mitchell Rabkin, President of the Beth Israel Hospital in Boston, discussed his hospital's decade of experience with policies concerning "do not resuscitate" (DNR) orders. He said such orders have become generally acceptable. Dr. Albert Fine, Director of the Intensive Care Unit at Somerville Hospital in Massachusetts, compared the policy and experience of a community hospital, such as his own, with those of a tertiary-care, teaching center, such as Beth Israel. He noted the reluctance of some older physicians to write DNR orders and warned that for some ethnic groups, explicit discussion of decisions not to resuscitate is very difficult and sometimes inappropriate.

Dr. Ned Cassem, a psychiatrist who is Chairman of the Critical Care Committee at Massachusetts General Hospital in Boston, discussed the explicit patient classification scheme once used at that hospital. Under this procedure, decisions

about the extent of treatment were guided by the "class" into which a patient is placed, based on a number of interrelated medical and nonmedical criteria. David Spackman, counsel to Boston's Board of Health and Hospitals, told the Commissioners that he has frequently received calls about the legal propriety of DNR orders and also noted that it has never been necessary for Boston City Hospital to seek court review for such an order.

The Commission also heard from Paul Rogers, a lawyer and founder of Guardianship, Inc. in Amherst, Massachusetts. He discussed the option of forming corporations to provide guardianship for institutionalized patients.

The final panel of witnesses consisted of clinicians who outlined medical considerations in foregoing life-sustaining treatment. Dr. Kevin McIntyre, a cardiologist at West Roxbury V.A. Hospital in Massachusetts, said that where prognosis is very poor and the family and medical staff are in agreement, termination of life-sustaining therapy is appropriate. Gen Foley, R.N., Assistant Director of Pediatric Nursing at Memorial Sloan-Kettering Hospital in New York, discussed the potential for meaningful long-term relationships with cancer patients, especially children. Dr. Paul Hardy, a neuropsychiatrist at Paul Dever State School in Taunton, Massachusetts, used the case of Earle Spring (a demented patient in a nursing home whose wife and son wished to stop his kidney dialysis) as an example that highlights the need for accurate professional assessment to undergird a determination of incompetence. The final witness was Dr. Ruth Purtilo, Associate Professor of Health Care, Ethics, and Humanistic Studies at Massachusetts General Hospital, who urged the Commission to look beyond high-technology measures in its consideration of life-sustaining care.

September 12, 1981

In Los Angeles, California, Commissioner Mario Garcia-Palmieri presided while testimony was taken from a panel of physicians and nurses who discussed their experiences with decisions about aggressive care. The panel included Sharon Imbus, a nurse at the the Burn Center at U.S.C. Medical School in Los Angeles; Dr. Norman K. Brown, a physician from Seattle, Washington; and Gary Wolfe, Director for Ambulatory Services for Peninsula Hospital in San Pedro, California. Imbus discussed decisionmaking involving burned patients for whom survival is unprecedented, including the patient's authority to decline all life-sustaining care. Dr. Brown presented his findings regarding the accepted practice of nontreatment of fever at proprietary and charitable nursing homes in Seattle. Wolfe reported that his hospital had assessed community needs two years previously and had found a substantial perceived need for flexible and responsive care for dying

patients. As a result, the hospital established a hospice, with emphasis upon symptom control, patient autonomy, and a multidisciplinary approach to comprehensive patient and family care.

The day's second session was chaired by Commissioner Frances K. Graham; the witnesses were Steve Lipton, an attorney who had been a legislative assistant to Assemblyman Barry Keene when the Natural Death Act was passed; William Thompson, a Ph.D. candidate in psychology and a law student at Stanford University; Sister Corinne Bayley, director of bioethics teaching for a group of hospitals in California; Dr. Francis Healy, a private practitioner from Burlingame, California, who chairs the California Medical Association (CMA) Committee on Evolving Trends; and Bruce Miller, a philosopher and assistant coordinator of the medical humanities program at Michigan State University who worked on the proposed Michigan Medical Treatment Decision Act.

Mr. Lipton stated that the legislative findings section of the preamble to the Natural Death Act, affirming the principle of autonomy in the face of fatal diseases, constitutes the Act's most significant portion. Thompson reported research on the understanding and use of the Natural Death Act, which demonstrated wide variability and substantial misunderstanding of the law among physicians. Sister Bayley testified that the Natural Death Act can be important in patient care when it leads to communication between patients and care givers but that it rarely changes preexisting decision patterns. Notwithstanding the broad statement of rights in the Act's preamble, she noted that the existence of legal liabilities has encouraged a perception among physicians and nurses that they are obligated to treat every patient with every possible beneficial modality of care not excluded by a valid "directive." She believes there ought to be little obligation to provide the intervention if it offers very little prospect of recovery.

Besides reporting the results of the CMA's survey on the use of "living wills," Dr. Healy testified that he believes patients want (and physicians are comfortable with) oral and joint decisionmaking, which is made awkward by written forms and technicalities. Dr. Healy also acknowledged that he usually talks with families about patients, but the content of the discussion is different than in conversations with patients. He stated that physicians do not and should not force explicit information upon patients. Miller reported on the model legislation that was proposed in Michigan for designating in advance a proxy decisionmaker and attributed the bill's failure to the opposition of the Right to Life Council and the Michigan Catholic Conference.

Commissioner Renée C. Fox presided over the afternoon sessions. The first panel, on actions leading to death, consisted

of Leslie S. Rothenberg, an attorney, and Dr. Robert Kaiser, who are Co-Chairmen of the Joint ad hoc Committee on Biomedical Ethics of the Los Angeles County Medical Association and the Los Angles County Bar Association; Dr. Lawrence Pitts, Chief of Neurosurgery at San Francisco General Hospital; Dr. Joseph K. Indenbaum, Medical Director of the County Department of Health Services; and George Oakes, Deputy District Attorney for Los Angeles County. Rothenberg reviewed the process that led to the ad hoc committee's "Guidelines for Discontinuation of Life-Support," which apply to mechanical respirators or ventilators, and outlined the guidelines' accomplishments and shortcomings. Dr. Kaiser reported that the guidelines have had some impact on physicians and have been the subject of substantial discussion. Oakes stated that the guidelines had been helpful by making the community standard of medical practice clearer, by clarifying the legality of certain actions, and by focusing public education and discussion.

Beginning with a description of "persistent vegetative state" (PVS), based on his studies of head injury, Dr. Pitts testified that he usually provides vigorous support for all potential PVS patients for the first month; before this time, he does not believe that the data are adequate to estimate prognosis reliably. If the patient remains vegetative thereafter, Dr. Pitts initiates no new therapy.

Dr. Indenbaum reported the origin, composition, and activities of the Citizen's Committee on Life-Support Policies, which promulgated guidelines for nonresuscitation ("no-code") in county hospitals.

The day's final panel discussed affirmative steps to end life in terminal situations. The first witness, Dr. Richard Scott, who is also a lawyer, spoke as General Counsel of Hemlock, a Los Angeles-based organization that supports legalization of active, voluntary euthanasia. Dr. Scott noted that although terminally ill patients who wish to die peacefully have the right to leave hospitals and die, doing so may entail substantial suffering and practical difficulties. He also argued that the distinction between voluntary and involuntary suicide is paramount; the *voluntary* request of the dying person should be a defense against charges of homicide or assisting suicide. The final witness was Edwin Shneidman, Professor of Thanatology at UCLA, who talked about the difficulties in assessing rationality and voluntariness.

During the time set aside for public comment, the Commission heard from Dr. Richard J. Lesco, of Torrance, California, who suggested that any policy with respect to consent regarding treatment of incompetent, dying patients should exonerate health care providers who make a "good-faith effort" to obtain consent from a relative or friend.

October 23, 1981

During a Commission meeting that discussed common themes in the Commission's work, James M. Gustafson, Professor of Theological Ethics at the University of Chicago, presented a case study on decisions to forego treatment of an infant in a neonatal intensive care unit. An extensive discussion ensued about the moral relevance of the effects on the family and involved health care personnel of a decision not to treat an infant. The Commissioners agreed that it is sometimes appropriate to consider the effects that extending a person's life has on the quality of life of others, but that serious ethical problems can arise when such considerations play a large part in individual decisions or when the economic effects are treated differently for people dependent on public programs from those who are not.

December 12, 1981

At this meeting, the Commissioners considered the issues raised by cardiac resuscitation of hospitalized patients and by the decision against resuscitation, as set forth in a paper drafted for possible inclusion in the report. Dr. Sol Edelstein, director of the emergency room at George Washington University Hospital in Washington, D.C., served as a resource person for the discussion. It was noted that the decision to write a "no-code" or "do not resuscitate" order assumes that death would be preferable to the life the patient would experience after resuscitation; moreover, since advance deliberation is possible, institutional policies to guide decisionmaking may be ethically and legally desirable.

The Commission also discussed treatment options for permanently unconscious patients, for which neurologist David Levy of Cornell University Medical Center in New York City served as a resource expert. Dr. Levy stated that the term "permanently unconscious patient" is a useful term to encompass subcategories of unconscious patients with different etiologies. Although prognosis studies for some subcategories are just beginning, Dr. Levy and his colleagues have found that the diagnosis can be made reliably for certain types of patients. In response to questions, Dr. Levy confirmed that from what is known of the nervous system it is highly unlikely that unconscious people feel pain.

January 8-9, 1982

During the first day of this hearing, the Commission continued the previous month's discussions of decisions to resuscitate hospital patients and of the care of those who are permanently unconscious. The thrust of the draft chapters was approved, and numerous suggestions were made for revisions in specific language and for the addition of further points.

On January 9, Commissioner Fox presided over the morning's discussion of neonatal intensive care, which began

with three witnesses from the Intensive Care Nursery at Children's Hospital in Washington, D.C. (Dr. Anne Fletcher, the Director; Carole Kennon, a social worker with major responsibility for the concerns of families; and Judy Brown, a nurse practitioner) and Jeanne Guillemin, a sociologist from Boston College who had spent over a year as a participant-observer in neonatal intensive care units in the United States and six other countries.

After Dr. Fletcher presented three case vignettes to illustrate the complexities of decisionmaking in neonatal intensive care, she and her colleagues described the team techniques used at Children's Hospital with parents who must suddenly face coping with decisions about their very ill newborn. The witnesses urged that nontreatment for babies with a very poor chance of recovery or of independent function should be possible and that the choice should rest principally with the parents.

The relationships among professionals, between the community and the hospital, and among hospitals were described by Guillemin, who pointed out that the setting is very complex from a sociological viewpoint. She listed some of the numerous decision points from delivery to resolution, noting that most of the serious conflict about treatment decisions comes from the inclusion of "marginal cases" within the sphere of treatment. She observed that, in other countries, clear guidelines exist to preclude referral of marginally viable newborns. Guillemin felt strongly that emphasis by public and private agencies on developing facilities and personnel for neonatal intensive care has not been balanced by appropriate concern for prevention of neonatal problems.

A second panel on the obligation to sustain the life of the infant consisted of John Fletcher, assistant for bioethics working at the National Institutes of Health; Philip Devine, Professor of Philosophy at the University of Scranton in Pennsylvania; and Mary Anne Warren, a Professor of Philosophy at San Francisco State University. Warren initiated the discussion by conceptualizing the factors that would, in her view, justify foregoing life-sustaining treatment, such as the expected length of an infant's life, its quality, and the effects of the treatment on family members. Devine disagreed with the thrust of these remarks; he stated his belief that a newborn must be considered to be as fully human and in the same situation as an incompetent adult who has not left prior directives. Fletcher said that medical criteria regarding outcomes should be primary and that the physician bears an obligation to present the facts with a recommendation as to the justifiable course of action; he was opposed, however, to allowing physicians to administer active euthanasia. Warren stated that in her view it is sometimes mandatory to kill in

order to prevent terrible suffering while dying. In regard to whether feeding an infant has a special moral claim, all panelists agreed that the claim to ordinary feeding is usually stronger than the claim for artificial feeding, and that there are reasons that justify foregoing artificial feeding that would not apply to ordinary feeding.

Commissioner Donald W. Medearis presided over the afternoon session, during which the elements of responsible decisionmaking about very sick newborns were discussed. The participants were Dr. Raymond Duff, a pediatrician involved principally in primary care residency training at Yale-New Haven Medical Center, who in 1973 co-authored the first systematic description of nontreatment decisions for infants; Dr. Norman Fost, a pediatrician who directs the medical ethics program at the University of Wisconsin Medical School at Madison; Dr. Peter Auld, a neonatologist who directs the neonatal intensive care unit at New York Hospital; and Dr. John Freeman, a pediatric neurologist working especially with children with spina bifida at Johns Hopkins Hospital.

Dr. Duff characterized the best procedures for decisions about life-sustaining therapy as those that are made in private and that rest on collaboration between family and physicians acting on their own ideologies. While recognizing that such decisions usually have some self-serving elements, Dr. Duff argued that the "pro-life" ideology misuses the homicide laws when it makes prudent and responsible decisions seem to be malicious. Dr. Fost characterized a high-quality proxy decision-maker as a dispassionate person who has the full facts and has disinterested status, and stated that parents frequently fall seriously short of this ideal. Dr. Auld pointed out that there are three major groups for whom decisionmaking problems arise: obvious nonsurvivors, patients without family members capable of participating effectively in decisions, and patients with chronically handicapping conditions compatible with a fairly long life. Dr. Freeman advocated that all babies should be intensively treated until the outcome is more clear even if this means having to (and being able to) actively kill some very handicapped survivors. Dr. Fost responded that active euthanasia could be moral and humane, but that there may be important social reasons to preclude active euthanasia. He emphasized the importance of avoiding the feeling of urgency in making decisions and the importance of a general preference to accept unwarranted suffering over unwarranted death.

In order to limit abuses of various forms of foregoing therapy, Dr. Fost recommended establishing institutional review boards on the model of those established for research. Dr. Duff agreed that procedural guidance is needed, but emphasized that such procedures should safeguard the integrity of the family.

February 13, 1982

The second day of the Commission's February meeting was devoted entirely to the issues arising from neonatal intensive care. The session was chaired by Commissioner Albert R. Jonsen, who suggested a tripartite classification scheme for seriously ill newborns: those who will die despite therapy, those for whom prolonged therapy will sustain life but not cure the affliction, and those whose life-threatening condition can be corrected but who will still have other, severe handicaps. The possibility of and justification for Jonsen's scheme and alternative ones were the subjects of the Commission's deliberations, with special emphasis on the diagnostic and prognostic uncertainties surrounding all categories. It was agreed that therapy may be foregone both in the first category and in the second category when it will be futile. The Commissioners rejected the notion that the decisions should be made according to a formula based on babies' weight, height, and so forth. The different meanings of "nonintervention" when no effective treatment exists and when medicine does possess the technical means of treatment were discussed; specific interventions were also discussed. The Commission concluded that these differences, as well as appropriate decisionmaking mechanisms, should be spelled out in the Report.

June 10-11, 1982

On the first day of this meeting, a panel of physicians focused on the potential import of the Commission's report for national health policy and clinical decisionmaking. The panelists included Dr. Ronald Cranford, a neurologist at Hennepin County Medical Center in Minneapolis, Minnesota; Dr. Mitchell Rabkin, Medical Director of the Beth Israel Hospital in Boston; and Daniel Callahan, Director of the Institute of Society, Ethics and the Life Sciences (the Hastings Center). Dr. Cranford noted the role of hospital ethics committees in facilitating communication, fostering education, and providing public accountability. While cautioning against viewing these committees as a decisionmaking panacea, Dr. Cranford noted that only a small percent of hospitals have such bodies and suggested more institutions should be encouraged to establish and evaluate them. Both Dr. Cranford and Dr. Rabkin praised the Commission's Report as advocating a good, balanced policy. Callahan urged that particular attention be paid to the costs of care for the dying and the social context into which the report would fit. The Commissioners and witnesses also discussed the changing attitudes of patients and providers toward foregoing life-sustaining therapy.

The morning's second panel, devoted to a conceptual analysis of the draft Report, included Dr. Callahan, from the first session; Joel Feinberg, Professor of Philosophy at the

University of Arizona in Tucson; and Richard A. McCormick, S.J., S.T.D., of the Kennedy Institute's Center for Bioethics in Washington, D.C. Much of their discussion centered on Chapter Two, especially its treatment of the traditional philosophical distinctions, such as acting versus refraining, intended outcomes versus merely foreseen consequences, and ordinary versus extraordinary treatment.

Feinberg termed critical the distinction between general rules and actions in individual cases and pointed out the need for legislatures to err on the safe side in seeking a balance between justified killings and unjustified prolongations of life, noting that permissibility does not always equal justifiability. Father McCormick expressed grave reservations about the discussion of the traditional distinctions, beginning with that of allowing to die versus killing. He suggested replacing the hypothetical case then included in that discussion with a series of examples more germane to the medical setting that would highlight dangers of abuse and coercion. Callahan cautioned against mixing questions of fact and value, and called the issue of what ought legitimately to be a part of a public policy statement the biggest problem for the report.

In a session devoted to comments from members of the public, Dr. James J. Smith, Director of the Nuclear Medicine Service at the Veterans Administration Central Office, speaking on his own behalf, disagreed with Father McCormick's view of the value of life for those incapable of human interaction, stating that communication might be possible even with patients in persistent vegetative state. John Paris, S.J., of the University of Massachusetts Medical School and Holy Cross College, urged that Chapter Two be revised and rewritten so that it could be of use in teaching medical students about ethical issues. Dr. Olga Fairfax, founder of United Methodists for Life, raised the recent case of Infant Doe in Indiana, calling the decision "not to treat" an Orwellian euphemism for starvation.

A panel on public policy and legal implications—Dr. Willard Gaylin, psychoanalyst and President of the Hastings Center; John Robertson, Professor at the University of Wisconsin Law School; and Robert Burt, Professor at the Yale Law School—made wide-ranging suggestions for improving the draft. Dr. Gaylin sounded a general call against lawyers' and philosophers' infatuation with hard cases and decried the popularity of framing issues in terms of "rights," with its tendency towards binary options and absolutes. He also urged a reevaluation of the Report's emphasis on the patient as an individual, in favor of a less isolated view of the patient as part of a network of family and friends. Robertson agreed with the tone of Chapters One and Two, but suggested they be more directly grounded in public policy questions. He also cautioned

that the establishment of ethics committees raises a number of legal issues, including composition, liability of members, legal effect of decisions, the source of authority, and the applicability of conspiracy and other criminal actions against ethics committee members who ratify decisions not to treat.

Burt urged increased attention to the possibility of education and training for those who deal with the dying as professionals, volunteers, or family members. Regarding incompetent patients, Burt urged a clearer identification of who is to be guardian, as well as a sharper delineation of the guardian's role, spelling out what training and capacities might be required. He suggested that the Report may encourage too ready resort to the courts, which might place too high a value on objectivity and leave no room for the moral ambiguity and anguish that should accompany decisions not to treat.

Finally, the Department of Health and Human Services' letter to hospitals warning that decisions to withhold treatment for handicapped newborns violates Federal law and could jeopardize their receipt of Federal funds sparked critical comments by both witnesses and the Commissioners.

On the second day of the June meeting the Commissioners continued deliberating on the draft Report, especially as it portrayed the standards and procedures for decisionmaking on behalf of patients who do not have the capacity to make their own health care decisions. It was also decided that the criticism of the traditional distinctions in Chapter Two should be less severe, since these distinctions are of continuing value—if the label does not merely serve to substitute for appropriate analysis—to people who must decide actual cases.

During the public comment session, Stephanie Ezrol of Lyndon Larouche's National Democratic Policy Committee read from the Nuremberg War Crimes Trial and said that legalizing "euthanasia" is tantamount to murder.

August 13, 1982

The morning session of this meeting was devoted to a discussion of the sections of the draft Report on the effect of institutional arrangements on the decisions of patients and on decisionmaking about seriously ill newborns. During the morning's public comment session Barbara T. Syska of Silver Spring, Maryland, urged more attention to the prevention of central nervous system defects in newborns.

October 8-9, 1982

The Commission considered in detail a draft of the full Report, directing the staff to make various modifications and expansions. During the session scheduled for public comment, the Commission heard from Harris Coulter, a medical historian, who pointed out the important role of third-party payors and hospitals, which in his view encourage continued treatment of patients on life-support systems because of the profit

motive. Earl Appleby, a staff member of Senator Jesse Helms (R-N.C.), speaking in his capacity as a private citizen, defended the medical profession against any venal motives in offering life-prolonging therapy, based upon the experiences he and his mother have had in caring for his comatose father at home for several years. Ronald Kokinda, representing the National Democratic Policy Committee, testified that decisions to forego life-sustaining therapy reflect a "cultural pessimism" and a giving-up on life. Dr. Dorothy Henneman, a practicing physician, encouraged the Commission to present and evaluate the philosophical issues involved in the Report.

November 12, 1982

The Commission discussed the modifications made in the draft, especially as they related to Chapter Two, and examined point-by-point the summary of conclusions in the introduction to the Report.

December 15, 1982

The Commission reviewed the changes directed at the November meeting and adopted the Report unanimously, with directions on necessary editorial changes and completion of the references before publication.

Mr. Fred Benjamin, a Department of Transportation employee, spoke on his own behalf concerning the importance of educating people to make informed medical decisions. A letter from Dr. Joseph G. Zimring, F.A.A.F.P., on decisions to forego treatment and on the definition of death was read into the record.

Supportive Care for Dying Patients: An Introduction for Health Care Professionals

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In few areas of health care are people's evaluations of their experiences so varied and uniquely personal as in their assessments of the nature and value of the processes associated with dying. For some, every moment of life is of inestimable value; for others, life without some desired level of mental or physical ability is worthless or burdensome. A moderate degree of suffering may be an important means of personal growth and religious experience to one person, but only frightening or despicable to another. Helping patients whose very definitions of what counts as health and disease are so different requires the utmost sensitivity and wisdom of health care professionals.

Dying has many common symptoms and manifestations; their medical treatment is considered in this Appendix. However, first it is important to remember that dying is not principally a "disease" calling for medical "remedies." Primarily, dying is the extinguishing of a human life, and those who provide medical care while patients are dying cannot effectively treat symptoms without caring for the patient as a person. Patients and their families will commonly be feeling great stress. The practitioner will have to be careful to accommodate the patient's priorities. Finding some meaning in death or saying farewell to family and friends may well be more important for a person than having a bowel obstruction treated or a dressing changed.

The goals for those who provide care for a dying patient include:

(1) Competent diagnosis, therapy, and prognosis. Medical skill and clinical acumen are extremely valuable as the patient's medical condition deteriorates, and compassion and respect for the patient ought never to be allowed to substitute for competent care.

(2) Symptom control to allow the patient to live as fully as possible.

(3) Advancing the patient's life goals and making available those experiences that the patient values.

(4) Personal loyalty and reliability. Trust is very important to the patient's peace of mind, and is undercut by unreliability, dishonesty, evasiveness, hubris, or abandonment by significant others.

(5) Help for family and friends during the patient's dying and during bereavement.

(6) Comprehensive attention, involving an appropriate team of care givers and an appropriate institutional or home setting. With such support, people who prefer to do so can usually die at home.

General Management

Skillful evaluation of a patient's history and physical examination and frequent review of the care plan will save dying patients more trouble than any drugs and tests could. Often, getting a definitive diagnosis of a complication would entail rehospitalization or distressing invasive procedures. However, knowledge of the natural history of a patient's diseases, the careful taking of an individual's history, and a skillful physical examination can in many cases make a presumptive diagnosis sufficiently certain to warrant the initiation of appropriate ameliorative therapy. Sometimes the diagnosis may be uncertain but all the remediable etiologies respond to fairly simple and acceptable therapies, so one or more treatment trials can be undertaken without a definitive diagnosis.

Often people who are dying have multiple organ failures, making deleterious side effects of drugs and therapies even more common than in their general application. Drugs cleared through the kidney almost invariably require reduced dosage, either in amount per dose or frequency.

The goals of medical practice should not be limited to improving a patient's health, but they must also include enhancing his or her self-respect and self-determination. For dying patients, who are in fact losing control over their lives in the most central way, control over the decisions that are still to be made is often very important. Some physicians deny this benefit through simple inattention or a rationalization that they are protecting the patient. Although patients expect tact and sympathy from their physicians, all available evidence indicates that they want to be included in decisionmaking about their care. Physicians and others who care for dying patients need to develop skills in communicating with patients and families so that most decisions about resuscitation, aggressive care, institutional arrangements, and symptom control remain the patient's.

Symptom Control

Nearly all dying patients have symptoms that can be relieved by judicious medical intervention. The symptom most feared in advance is pain, but mental function disturbances, nausea, diarrhea, constipation, infections, skin sores, and respiratory difficulty are also very distressing and often remediable as well. In this section some of the most common symptoms and approaches to controlling them are delineated.

Controlling symptoms sometimes requires relatively aggressive therapies.[1] The fact that a patient has only a few

[1] *See e.g.*, D.S. Robbie, *Addendum: Nerve Blocks and Other Proce-*

weeks or months left is *relevant* to the decision to use palliative radiotherapy or diverting colostomy—but a brief prognosis should not be taken to *preclude* these aggressive treatments. Rather, the individual's situation and likely course with each of various interventions should be considered carefully by the physician, other care providers, the patient, family, and friends. Sometimes, not only aggressive treatment of current symptoms but also aggressive treatment to forestall likely future symptoms is justified. Making the decision to undertake aggressive or risky treatments will often be unavoidably difficult, since it forces decisionmakers to confront the ambiguities of prognosis and the uncertainty of therapeutic effects.

Pain. Only a minority of dying patients—fewer than half of those with malignancies, for example—have substantial problems with pain,[2] yet many people fear pain while dying more than death itself. Acute pain, as from an injury, is the healthy body's way of protecting the injured part and taking steps to repair it. On the other hand, chronic and progressive pain often serves no useful function; instead it wastes the patient's strength and resolve and destroys whatever value he or she could have found in living. Fortunately, the chronic pain of dying patients in almost always fairly easy to control.

First, the care givers should seek a remediable cause: pathologic fractures, for example, usually deserve specific intervention rather than drugs.[3] In fact, pathologic fractures can often be averted by prophylactic nailing. Radiation therapy or chemotherapy of tumors can prevent or relieve symptoms, even when cure is not possible.

Second, anxiety and fear must be mitigated. Pain is extremely subjective. A standard painful stimulus is perceived

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dures, in Cicely M. Saunders, ed., THE MANAGEMENT OF TERMINAL DISEASE, Edward Arnold Publishers Ltd., London (1978) at 92; Thelma D. Bates, *Radiotherapy in Terminal Care, id.* at 119; Thelma D. Bates and Thérése Vanier, *Palliation by Cytotoxic Chemotherapy and Hormone Therapy, id.* at 125; Michael R. Williams, *The Place of Surgery in Terminal Care, id.* at 134; B.A. Meyerson, *The Role of Neurosurgery in the Treatment of Cancer Pain*, 74 ACTA ANESTH. SCAND. (Suppl.) 109 (1982); S. Arner, *The Role of Nerve Blocks in the Treatment of Cancer, id.* at 104; C. Bolund, *Pain Relief through Radiotherapy and Chemotherapy, id.* at 114. *See also*, a collection of general and specific articles in *International Symposium on Pain of Advanced Cancer*, in John J. Bonica *et al.*, eds., 2 ADVANCES IN PAIN RESEARCH AND THERAPY, Raven Press, New York (1979) (hereinafter cited as SYMPOSIUM ON PAIN); Robert G. Twycross and Vittorio Ventafridda, eds., THE CONTINUING CARE OF TERMINAL CANCER PATIENTS, Pergamon Press, New York (1980).

[2] Robert G. Twycross, *Relief of Pain*, in Saunders, *supra* note 1, at 66.

[3] *Id.* at 88-90.

as much worse if the patient is tired, afraid, isolated, or depressed.[4] Although some psychological problems warrant specific therapy (as discussed in the next section), surprisingly effective results can be obtained with a calm, competent, and reassuring approach by care givers. A nurse or physician who can say with assurance that a patient need never (or never again) feel overwhelmed by pain, and who proceeds to demonstrate the truth of the assertion, greatly eases the patient's mind and reduces his or her attentiveness to the pain. Conversely, the most potent stimulus to fear of pain, and thus to increased pain, is inadequately treated pain. Patients who obtain short periods of relief with a narcotic followed by periods of pain while waiting for a next dose become trained to fear the expected onset of pain while pain-free and to actively seek the drug constantly.[5] Such behavior commonly alienates hospital staff and leads to increased isolation. Adequate treatment for the pain can break this cycle.

Narcotics. If a patient's pain is uncontrolled, the primary aim is to control it; risking a period of sedation is not usually a contraindication to fully effective doses. For rapid and flexible control initially, intramuscular or subcutaneous[6] morphine is unsurpassed. In a patient who has not been on narcotics, 2-5 mg. parenterally (using a higher dosage with younger and heavier patients in better general condition and a lower one in frail, thin, or elderly patients or those with reduced respiratory reserve) given every 15-30 minutes with constant observation is uniformly effective. For patients who have been taking narcotics without sufficient relief, giving 1.5 to 2 times the previous dose is usually an effective alternative initial dose. Once the patient is untroubled or asleep, the care giver can judge how sensitive the patient is and how severe the pain, and a regular regimen can be started. If control was achieved with one or two low doses, non-opioid analgesics (see p. 284 *infra*) with or without codeine (30-60 mg. orally every 3-6 hours) may be sufficient. If more was needed, initial use of oral hydromorphone or morphine is probably better.

Control of pain with narcotics involves continual experimention to keep the dose in the zone between oversedation on the one hand and recurrence of pain on the other, so that the patient stays fairly alert but pain-free. Most patients have a

[4] *Id.* at 68; C. Richard Chapman, *Psychologic and Behavorial Aspects of Cancer Pain*, in SYMPOSIUM ON PAIN, *supra* note 1, at 45.

[5] Twycross, *supra* note 2, at 71-72.

[6] The effectiveness and time course of narcotics is approximately equal for intramuscular and subcutaneous adminstration. Jerome H. Jaffe and William R. Martin, *Opioid Analgesics and Antagonists*, in Alfred Goodman Gilman, Louis S. Goodman, and Alfred Gilman, eds., GOODMAN AND GILMAN'S THE PHARMACOLOGICAL BASIS OF THERAPEUTICS, Macmillan Pub. Co., New York (6th ed. 1980) at 494.

substantial "therapeutic window," though what doses achieve it and at what frequency do change over time.[7] For a few patients, especially when death is close, there is no such zone and the physician, with the patient's or family's concurrence, must be willing to accept sedation if pain is to be avoided.

Oral medications are preferred to parenteral whenever possible.[8] Of course, patients demonstrate substantial variability in their oral-parenteral ratio with each drug[9] and similar variability in their individual ratio between drugs.[10] However, all narcotics are less potent orally, sometimes dramatically so[11] (see Table B1, p. 281 *infra*). Oral administration gives more constant blood and cerebrospinal fluid levels than intermittant parenteral dosing. Furthermore, parenteral administration to a dying patient so often becomes difficult as the muscle mass wastes and the superficial circulation is reduced. The patient also has more control over the oral route. Many patients find liquid preparations easier to take than tablets and capsules. A few patients benefit from the availability of narcotic suppositories[12] (morphine, hydromorphone (Dilaudid 3 mg.), or oxymorphone (Numorphan 5 mg.)) but bioavailability is variable. Yet suppositories can sometimes permit home care when a patient's family cannot administer injectable medications.

Physicians should become very familiar with a small number of narcotics, rather than using each of the numerous preparations only occasionally. Codeine for moderate pain, morphine or hydromorphone for moderate or severe pain, and methadone (Dolophine) or levorphanol (Levo-Dromoran) for fairly stable severe pain are sufficient for almost all narcotic needs. Codeine in usual doses has moderate efficacy, lasts 3-6 hours when given orally, and has few side effects except constipation and occasional nausea.

Morphine and hydromorphone are usually effective for about 3-4 hours and the dosage can be increased sufficiently to overcome almost any severe pain. At higher doses, morphine is thought to be more reliable than hydromorphone but it may cause nausea more often. However, hydromorphone is easily abused and is therefore sometimes difficult to obtain from

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[7] Twycross, *supra* note 2, at 71-72, 83-85; William T. Beaver, *Management of Cancer Pain with Parenteral Medication*, 244 J.A.M.A. 2653 (1980); L.K. Paalzow, *Pharmacokinetic Aspects of Optimal Pain Treatment*, 74 Acta Anesth. Scand. (Suppl.) 37 (1982).

[8] Beaver, *supra* note 7.

[9] Jaffe and Martin, *supra* note 6, at 507-09.

[10] Jack McKay Zimmerman, Hospice: Complete Care for the Terminally Ill, Urban & Schwarzenberg, Baltimore (1981) at 67.

[11] Jaffe and Martin, *supra* note 6, at 505-506; Charles E. Inturrisi, *Narcotic Drugs*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 The Medical Clinics of North America 1061 (1982).

[12] Twycross, *supra* note 2, at 76.

Table B1:

Approximate Equianalgesic Doses of Narcotics When Used for Chronic Pain*

Drug	P.O. (mg.)	I.M. or SQ. dose (mg.)	Usual Effective Interval (hrs.)
Codeine	200†	130†	3-4‡ i.m. and sq., 4-6 p.o.
Morphine	40**	10 mg.	3-4 i.m. or sq., 4-6 p.o.
Hydro-morphone	7.5	1.5	3-4 i.m. or sq., 4-6 p.o.
Methadone	20	10	longer††
Levorphanol	4	2	longer‡‡

* Doses from Raymond W. Houde, *Systemic Analgesics and Related Drugs: Narcotic Analgesics*, in John J. Bonica and Vittorio Ventafridda, eds., International Symposium on Pain of Advanced Cancer, 2 Advances in Pain Research and Therapy, Raven Press, New York (1979) at 266; modified as noted. Intervals from personal communication with Dr. Raymond Houde (Jan. 1983), modified as noted.

† Although these are the approximate doses of codeine to equal the analgesic effect of 10 mg. parenteral morphine, patients who need more than 100 mg. codeine orally or 60 mg. parenterally usually are switched to one of the more potent drugs. The ratio of oral codeine to oral morphine for equianalgesia is quite variable, having been reported to be as much as 13:1; R.W. Houde, S.L. Wallenstein, and W.T. Beaver, *Clinical Measurement of Pain*, in G. deSteuras, ed., Analgetics, Academic Press, New York (1965) at 75, 92.

‡ The effective interval for codeine is often given as 4-6 hours; *see e.g.*, Alfred Goodman Gilman, Louis S. Goodman, and Alfred Gilman, eds., Goodman and Gilman's The Pharmacological Basis of Therapeutics, Macmillan Pub. Co., New York (6th ed. 1980) at 507. Many clinicians are finding (and Houde has confirmed in cross-over studies) that the effective interval is actually close to that of morphine, about 3-4 hours, especially in parenteral administration; personal communication with Dr. Raymond Houde (Jan. 1983).

** There is substantial uncertainty as to the correct oral-parenteral ratio for morphine. In single doses, the ratio is conventially given as 6:1 (oral:parenteral); Gilman, Goodman, and Gilman, *supra* note ‡, at 507; Houde, *supra* note*, at 266. However, in chronic use, the ratio seems to be lower. Robert G. Twycross, *The Brompton Cocktail*, in Bonica and Ventafridda, *supra* note*, at 291, 293, postulates a ratio with morphine solution of 3:1 (oral to parenteral). Others feel it may well be as low as 2:1; Paul D. Henteleff and Elliot Fingerote, *Clinical Study of Relative Effectiveness of Narcotics*, at the 5th Annual Meeting and 8th Symposium of the National Hospice Organization, Washington, Nov. 9, 1982. The value used here, 4:1 (oral to parenteral) was suggested by Dr. William Beaver (personal communication, Dec. 1982) as a reasonable estimate for the usual progression from oral medications to parenteral, which, in potentially underestimating the correct dose, entails a readily remediable error.

†† The best dosing interval for methadone is uncertain. Despite a long plasma half-life (15-30 hours; Charles E. Inturrisi, *Narcotic Drugs*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 The Medical Clinics of North America 1061, 1065 (1982)), the analgesic effect parenterally often is

only as long as morphine (*e.g.*, 3-5 hours; personal communication from Raymond Houde, Jan. 1983). Yet, using methadone at such frequent intervals often leads to confusion in the first few days. In chronic use, methadone might be given frequently (every 4 hours) for the first 24 hours, then the interval reduced to 1-3 times per day or the dosage reduced; L. Paalzow, L. Nelson, and P. Stenberg, *Pharmacokinetic Basis for Optimal Methadone Treatment of Pain in Cancer Patients*, 74 ACTA ANESTH. SCAND. (Suppl.) 55 (1982). *See also*, J. Säwe *et al., Patient-controlled Dose Regimen of Methadone for Chronic Cancer Pain*, 282 BRIT. MED. J. 771 (Mar. 1981); David S. Ettinger, Paul J. Vitale, and Donald Trump, *Important Clinical Pharmacologic Considerations in the Use of Methadone in Cancer Patients*, 63 CANCER TREATMENT REPORTS 457 (1979).

‡‡ Robert G. Twycross, *Relief of Pain*, in Cicely M. Saunders, ed., THE MANAGEMENT OF TERMINAL DISEASE, Edward Arnold Publishers Ltd., London (1978) at 66, 77-78, gives this interval for levophanol. Its pharmacokinetics and existing research base parallel methadone, though its structure is different and its plasma half-life is shorter (12-16 hours, Inturrisi, *supra* note †, at 1065). It may be similar in having a relatively brief analgesic effect, especially in the first few days of use, and a tendency to accumulate with detrimental mental effects unless dosage is reduced.

from outpatient pharmacies. The volume of narcotic for intramuscular use or the number of tablets for oral use can become unsettling to the physician or nurse and unacceptable to the patient. The professional should be reassured to know that some patients have required over 300 mg. of morphine orally every 3 hours and over 200 mg. intramuscularly every 2-3 hours. As long as the patient is awake and in pain, the dose is not too high. However, such high doses may entail many tablets or unacceptably large or frequent parenteral injections. To reduce the volumes for parenteral administration over commercially available solutions, crushed hypodermic morphine sulfate tablets can be dissolved in warmed sterile water. At some point, intravenous morphine may be better. Morphine can be added to dextrose or electrolyte solution in whatever concentration is necessary, usually 1 mg./ml. initially. To prevent accidental overdose, either an automated rate control device or a 1-2 hour infusion volume (as in a Soluset) should be used. These high doses are the only time when diamorphine (heroin) offers an advantage, since its potency and solubility are so much higher that parenteral volumes remain low.[13] Hydromorphone is also very soluble, but concentrated solutions must be made up from the powdered drug and filtered by a pharmacist.

For patients who seem to be stable for a period of weeks or months, a longer-acting narcotic is sometimes helpful. Either methadone or levorphanol can at times be given orally two or three times a day, thereby allowing the patient to sleep all night and to go about daily tasks without constantly attending to the next drug dose. Some patients use one of these most of

[13] *Id.* at 76-77. Diamorphine is not legally available in the United States.

the time but take a shorter-acting agent as a booster shortly before activities known to worsen pain, such as taking a bath or transferring from bed to chair. Methadone is reported to have a tendency to accumulate and induce oversedation or confusion.[14]

The physician should know approximate equivalences of the most common narcotics preparations and delivery routes so that switching among regimens is as smooth as possible (see Table B1, p. 281 *supra*). Cross-tolerance is fairly great, but not complete.[15] Thus it is wise to use about one-quarter less than the predicted dose of a new narcotic for the first dose, possibly with a supplement in an hour if needed.

All narcotics should be given on a fairly regular schedule aimed to anticipate the recurrence of pain by having each dose take effect just as the last one is waning. Sometimes patients who are getting adequate pain relief for too short a period respond better to increased frequency than to increased dosage. In settings where the nurse or other person directly caring for the patient understands the pharmacology involved, writing orders "prn" is reasonable, as it is interpreted to mean "as needed to prevent recurrence of pain without undue sedation." In the usual hospital setting where "prn" might be interpreted to mean "when pain recurs," narcotics should be given on a regular schedule and adjustments made on the basis of frequent observation by the physician.[16] When a previously adequate dosage schedule becomes inadequate and no remediable cause is found, the patient will often need a potentiating drug or to have the total dose of the current narcotic nearly doubled to regain good effect.

Whenever narcotics are used, certainly with dying patients, flexibility and confidence are increased by always having naloxone (Narcan, 0.4 mg./ml.) available. One milliliter (intravenous, intramuscular, or subcutaneous) will usually substantially reverse oversedation and respiratory depression, and that dosage may be repeated each 2-3 minutes until 3 ml. have been given.[17] Usually, just letting the patient sleep until a

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[14] *Id.* at 78; Kathleen M. Foley, *The Practical Use of Narcotic Analgesics*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1091, 1094-95 (1982). *See also* explanatory note ††, Table B1 at p. 281 *supra*.

[15] Raymond W. Houde, *The Use and Misuse of Narcotics in the Treatment of Chronic Pain*, in J.J. Bonica, ed., 4 ADVANCES IN NEUROLOGY, Raven Press, New York (1974) at 527.

[16] Marcia Angell, *The Quality of Mercy* (Editorial), 306 NEW ENG. J. MED. 98 (1982); Beaver, *supra* note 7, at 2655-56; for documentation of the current serious underutilization of narcotics, *see* Richard M. Marks and Edward Sachar, *Undertreatment of Medical Inpatients with Narcotic Analgesics*, 78 ANNALS INT. MED. 173 (1981).

[17] Jaffe and Martin, *supra* note 6, at 523-25. More tolerant and dependent patients are paradoxically sensitive to naloxone. There-

mild overdose is metabolized is appropriate, but using naloxone allows for more diagnostic certainty and protection against drug-induced respiratory insufficiency.

Narcotics commonly cause or worsen constipation and nausea, but these effects can be prevented and treated.[18] Pharmacologic agents to counteract constipation exacerbated by narcotics often are effective only at 2 to 3 times their usual dosage.

Concerns about dying patients becoming addicted to narcotics are both mistaken and, in any case, irrelevant. Few patients develop problems because of physical dependence. Furthermore, if the cause of pain is relieved, narcotics can be discontinued over a few days without untoward effects.[19] Furthermore, physical and psychological addiction, when it occurs, is not particularly troubling to a patient who is dying, nor should it be to care givers.

Other analgesics and potentiators. Acetaminophen, aspirin, and the group of nonsteroidal anti-inflammatory agents (including indomethacin and phenylbutazone) are often adequate for the control for pain. They act by different mechanisms than narcotics, with additive or supra-additive effects, thus allowing reduction in narcotic dosage in many cases.[20] Also, their anti-inflammatory effects may directly relieve some sources of pain such as arthritis, contractures, or wounds. Of course, the risks of side effects such as gastritis or gastrointestinal bleeding must be considered.

Agonist-antagonist drugs like pentazocine (Talwin), butorphanol (Stadol), and nalbuphine (Nubain) are potent analgesics, though they do have ceiling effects and tend to cause psychotomimetic effects at high dose. But butorphanol and nalbuphine are only available for parenteral use and have not been well evaluated in chronic pain of dying patients. Pentazo-

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fore, the standard naloxone preparation might best be diluted and administered in fractionated doses to reduce risk of inducing withdrawal and severe recurrent pain. For patients with tolerance, naloxone reversal is likely to have to be repeated over the ensuing few hours. Gilman, Goodman, and Gilman, *supra* note 6, at 523.

[18] *See* pp. 289-91 *infra*.

[19] Jane Porter and Hershel Jick, *Addiction Rare in Patients Treated with Narcotics*, 302 NEW ENG. J. MED. 123 (1980); Twycross, *supra* note 2, at 82-85.

[20] Thomas G. Kantor, *Control of Pain by Nonsteroidal Anti-Inflammatory Drugs*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1053 (1982); Charles G. Moertel, *Relief of Pain in the Cancer Patient*, in Stephen K. Carter, Eli Glatstein, and Robert B. Livingston, eds., PRINCIPLES OF CANCER TREATMENT, McGraw-Hill Book Co., New York (1982) at 199; Twycross, *supra* note 2, at 72-73; R.W. Houde, S.L. Wallenstein, and N. Rogers, 1 CLINICAL PHARMACOLOGY AND THERAPEUTICS 163 (1960).

cine causes many adverse reactions, especially in the elderly, and is not especially flexible. A weaker tendency to cause addiction is not especially advantageous in dying patients; and, as these drugs are narcotic antagonists, they cannot be used in an integrated program with narcotics—one that relies on increasing efficacy of drugs as pain worsens or tolerance develops. Thus, pentazocine and other agonist-antagonist drugs have at this time little use in managing the pain of dying patients.[21]

Other drugs—such as hydroxyzine (Vistaril, Atarax)[22] and tricyclic antidepressants[23]—may potentiate narcotics. Usually patients with pain have reason for one or another of these, and the benefit of potentiation of narcotic effect is welcome. Theoretically, narcotic overdose could be induced in starting a potentiating drug, but this is rarely a problem. Benzodiazepenes and phenothiazines probably do not potentiate narcotics.[24]

Steroids, most commonly prednisone or dexamethasone, help control pain that arising in osseous metastases or fractures. Usually, maximum effect is at fairly low pharmacologic doses, about 2-4 mg. per day of dexamethasone or 10-20 mg. daily of prednisone.[25]

Neurosurgical and anesthetic methods. Localized pain, especially from pain fibers low in the spinal cord or in a limb, are sometimes accessible to temporary or permanent pain tract disruption.[26] Short-term blocks are useful for diagnosis but usually counterproductive for long-term pain control. Some initial testing of epidural morphine shows promise, however.[27]

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[21] Twycross, *supra* note 2, at 74.

[22] William T. Beaver and Grace Feise, *Comparison of Analgesic Effects of Morphine Sulfate, Hydroxyzine, and Their Combination in Patients with Postoperative Pain*, in J.J. Bonica and D. Albe-Fessard, eds., 1 Advances in Pain Research and Therapy, New York, Raven Press (1976) at 553.

[23] Robert G. Twycross, *Overview of Analgesics*, in Symposium on Pain, *supra* note 1, at 617, 622; Lawrence M. Halpern, *Psychotropics, Ataractics, and Related Drugs*, in *id.* at 279.

[24] J.W. Dundee and J. Moore, *The Myth of Phenothiazine Potentiation* 16 Anaesthesia 95 (1961); *but see*, Ross J. Baldessarini, *Drugs and the Treatment of Psychiatric Disorders*, in Gilman, Goodman, and Gilman, *supra* note 6 at 391, 414.

[25] Twycross, *supra* note 23, at 625; Twycross, *supra* note 2, at 88-90.

[26] Robbie, *supra* note 1; Meyerson, *supra* note 1; Arner, *supra* note 1; Bolund, *supra* note 1.

[27] L. Mandaus, R. Blomberg, and E. Hammars, *Long-Term Epidural Morphine Analgesia*, 74 Acta Anesth. Scand. (Suppl.) 149 (1982); Lawrence Sherman, Robert Milch, and George Cohn, *The Use of Epidural Morphine in a Hospice Setting*, presented at the Fifth Annual Meeting and Eighth Symposium of the National Hospice Organization, Washington, Nov. 9, 1982.

Determining whether the destruction of a nerve, spinal cord tract, or brain center is warranted requires consultation with an experienced anesthesiologist and/or neurosurgeon. The patient considering an ablative procedure should be well aware of the likelihood and seriousness of the possible loss of additional neurologic functions. The patient should ordinarily have had a trial of vigorous nondestructive pain control.

A mixture of 50% nitrous oxide and 50% oxygen may be useful for patients with short-lived severe pain, as in dressing changes or movement.[28]

Mental Function

Preexisting disturbances. Patients who are dying are not all the same; severe depression, alcohol abuse, psychosis, dementia, and personality disorders are as prevalent among these patients as among others. Treatment of the symptoms of these disorders as the patient is dying will usually entail the same sorts of methods used with healthier patients: drugs, behavioral modification, environmental control, and so forth. People giving care to dying patients must be especially careful, however, to set reasonable goals and limits and to focus more on accepting these patients than on changing them.

Primary central nervous system disease. The changes in mental functions that patients dying of strokes, dementias, or space-occupying intracranial lesions experience are often more disturbing to family members and care givers than to the patients themselves since they are often unaware of their situations. When these lesions cause distressing behavior, antispasmodic drugs or tranquilizers may be useful. When increased intracranial pressure could be a component, dexamethasone (2-32 mg. per day in 4-8 doses) may be tried,[29] though it has a number of potential side effects. If dexamethasone is successful, the dosage can be reduced to lowest effective level. If the intracranial process is enlarging, symptoms will recur and high doses might again be warranted. When dexamethasone no longer proves to be significantly beneficial, rapidly tapering it to baseline adrenal replacement (about 2 mg. per day) or lower is often warranted, as this allows the terminal phase to be mercifully brief.

Drugs and metabolic abnormalities. Hypercalcemia is a particularly common concomitant of malignancies and can cause myriad symptoms, the most common being confusion, disorientation, and sedation. If this occurs as the patient is

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[28] Twycross, *supra* note 2, at 98.

[29] Mary J. Baines, *Control of Other Symptoms*, in Saunders, *supra* note 1, at 99, 102-03; Plum recommends 16 mg. initially and 4 mg. every 6 hours, tapering if possible. Fred Plum, *Headache*, in James B. Wyngaarden and Lloyd H. Smith, eds., CECIL TEXTBOOK OF MEDICINE, W.B. Saunders Company, Philadelphia (16th ed. 1982) at 1948-49.

close to death anyway, it may be best to accept hypercalcemia without therapy, as few deaths are more gentle. However, if calcium rises when a patient might have a few weeks or more of valued life left, therapy may be warranted.[30] Increased fluids and furosemide (Lasix) often suffice; adrenocortical steriods and oral phosphates are also often effective. Sometimes mithramycin (Mithracin), even at as low a dose as 1-2 mg. intravenously once or twice a week, is effective. Calcitonin (Calcimar, 50-100 MRC daily or on alternate days) might also be used.

Since dying patients are often cachectic, vitamin-deficient, acidotic, hypo-osmotic, uremic, hypoalbuminemic, or hypoxic they are likely to experience mental changes from drugs that do not usually have such effects. Sedatives and tranquilizers are obviously common culprits, but so are cimetidine, digoxin, tricyclic antidepressants, theophylline, steroids, and other "medical" drugs. Narcotics rarely cause confusion without concomitant severe sedation, though some patients find all narcotics to be dysphoric. When changes in a patient's mental status interfere with the patient and family living as fully as possible, each drug that could be causing the mental change should be reduced as much as possible to test whether mental function is improved.

Metabolic abnormalities like hypoxia, hepatic failure, renal failure, acidemia, hypokalemia, hypomagnesemia, and dehydration are not uncommon causes of mental disturbances and might be remediable.

Anxiety and depression. Some anxiety and depression are normal in dying patients. Most of what is truly troublesome to the individual is best relieved by simple psychological support, pain control, attention to legal, social, and financial problems, and so forth.[31]

Free-floating anxiety or persistent depression can have crippling effects on some patients. Fortunately, both commonly respond to fairly mild pharmacologic agents and supportive psychotherapy.[32] Many patients benefit from fairly low doses of tricyclic antidepressants.[33] A dose as low as 20-30 mg. of doxepin (Sinequan) or nortriptyline at bedtime often encour-

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[30] Baines, *supra* note 29, at 101; Zimmerman, *supra* note 10, at 68.

[31] Colin M. Parkes, *Psychological Aspects*, in Saunders, *supra* note 1, at 44.

[32] *Id.* at 56-57; Baines, *supra* note 29, at 114; Peter G. Wilson, *Anxiety and Depression in Elderly and Dying Patients*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1011, 1015 (1982).

[33] Alexander H. Glassman and Steven P. Roose, *Tricyclic Drugs in the Treatment of Depression*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1037, 1040 (1982).

ages a good night's sleep, reduces anxiety, and improves appetite.

Numerous other anxiolytic agents can be used: antihistamines, benzodiazepines, phenothiazines, and so forth. Often, one or another is indicated for a separate reason; prochlorperazine (Compazine), for example, is used to reduce both nausea and anxiety. Benzodiazepines are somewhat risky as they have a long half-life and a fairly high incidence of causing confusion or sedation.[34] Hydroxyzine (Vistaril or Atarax, 10-25 mg. every 6-8 hours) has some advantages in that it potentiates narcotics, reduces nausea, can be given orally or parenterally, is fairly effective, and has few sedative or anticholinergic side effects even in elderly or debilitated patients.

Gastrointestinal Symptoms

Anorexia and dysphagia. For a patient to find himself or herself uninterested or averse to food can be quite disconcerting for the person, and often even more so to family members. However, substantial anorexia is almost the norm in the later stages of terminal illness. Sometimes counseling family and patient to accept a loss of appetite is extremely helpful. An altered sense of taste or smell is sometimes part of the cause of anorexia. Stronger flavors, careful menu selection, and good mouth care may help.

Other interventions include a little of the patient's favorite alcoholic beverage (or Gevrabon, which contains vitamins dissolved in sherry) 30 minutes before meals, small and attractive-looking meals on a flexible schedule, a vitamin and mineral supplement, high-calorie milk shakes or prepared dietary supplements, low-dose steriods (*e.g.*, 1 mg. dexamethasone or 5 mg. prednisone three times daily), or tricyclic antidepressants.[35]

Only rarely should a dying patient be fed by tube or intravenously. When neurologic or structural disease of the mouth or esophagus precludes the swallowing of food, tube feeding might be warranted if chosen by an individual on a well-informed basis.[36] When initiating any sort of artificial feeding with a dying patient, the practitioner would do well to talk with the person and/or family about indications that would warrant its discontinuation.

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[34] B. Robert Meyer, *Benzodiazepines in the Elderly*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1017 (1982).

[35] Zimmerman, *supra* note 10, at 69-70.

[36] Michael R. Williams, *The Place of Surgery in Terminal Care*, in Saunders, *supra* note 1, at 134, 136; Zimmerman, *supra* note 10, at 70-71. *But see* Joyce V. Zerwekh, *The Dehydration Question*, Nursing83 47 (1983), which argues that dehydration is normal and prevents distressing symptoms in the last few days of life.

In the unusual case where dysphagia is due to candidiasis or is avoidable by the justified use of a feeding tube, dysphagia is remediable. More commonly, a feeding tube is not warranted and the cause is not correctable; sedation and pain relief may then be all that is indicated.

Problems with the mouth. Much avoidable distress arises from inattention to the mouth.[37] Early in the course of a predictably fatal illness, patients should be encouraged to have dental care. Abcesses, exposed roots, and ill-fitting dentures are likely to be more of a problem as the patient loses weight and fights infections less successfully. Dentures should be used as long as possible despite receding gums, especially since patients often feel ashamed to be seen without them. Regular brushing of the teeth and cleaning of the mouth can often improve the patient's self-image greatly. Candidiasis is usually easy to diagnose and treat, using nystatin (Mycostatin) either as a suspension or as oral tablets (5 ml. to swish, or one oral tablet to suck and swallow 3-4 times a day).

Dehydration, head and neck surgery, radiation to the face and neck, mouth breathing, narcotics, and anticholinergics make dry mouth a common problem. Frequent tooth brushing and mouth rinsing help, as do sipping liquids, sucking on ice, or sucking on hard candies. Commercial artificial saliva (Moi-Stir) or a specially prepared mixture of methylcellulose and glycerin or lemon essence can also be helpful.[38]

The inability to speak or to speak clearly is often very distressing to patients, families, and care givers. The usual methods of speech therapy—sign boards, typewriters, note pads, and lip reading—generally suffice to restore some communication. Often, however, care givers must be even more willing than normal to try to guess the patient's concerns and to initiate the relevant conversations.

Nausea and vomiting. Many seriously ill patients have nausea and vomiting. Sometimes the cause can be corrected. If not, prochlorperazine (Compazine) or a related phenothiazine is usually the most effective therapy. Doses can be clustered (*e.g.*, 5 mg. every 20 minutes up to 4 doses, to repeat every 6 hours as needed) in response to intermittent symptoms or can be scheduled (*e.g.*, 10-20 mg. orally or intramuscularly every 8 hours or 25 mg. per rectum every 6 hours) in response to more continuous symptoms.[39]

Delta-9-tetrahydrocannabinol (THC) is a component of marijuana that is showing promise in early investigations

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[37] Austin H. Kutscher, Bernard Schoenberg, and Arthur C. Carr, THE TERMINAL PATIENT: ORAL CARE, Columbia Univ. Press, New York (1973).
[38] Baines, *supra* note 29, at 99-100.
[39] Zimmerman, *supra* note 10, at 71.

concerning nausea and vomiting associated with chemotherapy.[40] Oral metoclopramide (Reglan) may be useful to treat nausea and vomiting if gastric atony and reduced intestinal motility are contributing causes.[41] Sometimes an antihistamine (*e.g.*, dimenhydrinate (Dramamine)) can be helpful also.

Intestinal obstruction. Some nausea and vomiting originate with intestinal obstruction. If the obstruction is from fecal impaction, cathartics, enemas, manual disimpaction, and hydration may solve the problem. With other causes, abdominal surgery will have to be considered. In addition to nausea and vomiting, intestinal obstruction can cause pain, infection, dehydration, and malnutrition.

One need not always try to relieve the obstruction, however. When the obstruction is unifocal and low and the patient could otherwise live for some weeks or months, a diverting colostomy may be helpful palliation. But when the obstruction is multifocal or high or when a patient has at best only a few weeks to live, it may be best to treat the symptoms only.[42] The pain and hyperperistalsis will usually respond to adequate use of narcotics. Antiemetics and frequent small feedings allow for some absorption, and most patients remain quite comfortable until death, often without nasogastric suctioning or intravenous fluids.

Constipation and diarrhea. Decreased bulk in the diet, inactivity, abdominal disease, metabolic imbalance, dehydration, anticholinergic drugs, and narcotics combine to make constipation the norm for dying patients. Untreated, constipation can cause bowel obstruction, diarrhea, fever, pain, and confusion. Obviously, bowels should receive close attention. Stool softeners such as dioctyl sodium sulfosuccinate (Colace) or psyllium hydrophilic muciloid (Metamucil) should be given regularly. Stimulants such as casanthranol (as in Peri-Colace), senna derivatives (Senokot), cascara sagrada, or bisacodyl (Dulcolax) should be added as needed. Mineral oil, milk of magnesia, or other agents may be preferred by some patients.

If no stools are passed for three days, a rectal examination is in order. If stool is present but not impacted, the digital exam, glycerin suppositories, bisacodyl suppositories, and prepackaged enemas should be used, probably in about that sequence. No stool by the fourth day should elicit the same response, with the addition of vigorous enemas (soap suds, warm oil, or high volume). With assiduous attention and

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[40] *Id.*

[41] Baines, *supra* note 29, at 103; Riyad Albibi and Richard McCallum, *Metoclopramide: Pharmacology and Clinical Application*, 98 ANN. INT. MED. 86 (1983).

[42] Zimmerman, *supra* note 10, at 71-72; Baines, *supra* note 29, at 101-02.

vigorous efforts, nearly all patients can avoid the complications of constipation.[43]

Diarrhea is a less common problem, but it may be caused by diabetes, antibiotics, underlying malabsorption, and fecal impaction. If it is due to pancreatic insufficiency, diarrhea can be dramatically relieved by replacement enzymes.[44] If the cause cannot be removed, the diarrhea can usually be stopped with diphenoxylate with atropine (Lomotil, 1 or 2 tablets after each stool, up to 8 per day) or loperamide (Imodium, 2-4 mg. after each stool up to 16 mg. per day).

Ascites. Ascites is often asymptomatic despite being dramatic. When troubling, cirrhotic ascites may respond to the usual diuretics or the less usual shunting. Malignant ascites often is well controlled by instillation of chemotherapeutic agents or by frequent paracenteses, which are both well tolerated.[45]

Skin Problems

Decubitus ulcers. Cachectic, immobile, and bedbound patients are at great risk of developing skin sores. Few patients without them realize how distressing these lesions can be. Prevention, or at least a delay in their onset, is much more satisfactory for patients than efforts to heal an established decubitus ulcer. Frequent turning, skin massage, padding around prominent bones and ears, and redoubled efforts if the skin starts to redden are the hallmarks of prevention. Immobile patients should have heel protectors and one of the various special mattresses (egg-crate, water bed, air mattresses, or the like). For some patients, an overhead trapeze is an invaluable encouragement to make frequent position changes.

Few decubiti in dying patients heal. Once the skin breaks, usually all that can be done is to keep infection from being serious and to keep the lesion from enlarging. Usually about once a month, cellular debris needs to be cleared with a week of wet-to-dry dressings or sharp dissection. Various local therapies are promoted, though none has been shown to be distinctly superior in controlled trials.[46]

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[43] Baines, *supra* note 29, at 104-05; Harvey Klein, *Constipation and Fecal Impaction*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 THE MEDICAL CLINICS OF NORTH AMERICA 1135 (1982).

[44] Baines, *supra* note 29, at 105.

[45] Charles G. Moertel, *The Peritoneum*, in James F. Holland and Emil Frei, III, eds., CANCER MEDICINE, Lea & Febiger, Philadelphia (1973) at 1631, 1632.

[46] James B. Reuler and Thomas G. Cooney, *The Pressure Sore: Pathophysiology and Principles of Management*, 94 ANNALS INT. MED. 661; Joseph Agris and Melvin Spira, *Pressure Ulcers: Prevention and Treatment*, 31 CLINICAL SYMPOSIA 5, 7 (1979).

Other open lesions. Some patients have fistulas or sinuses whose care presents a problem. Sometimes excision, amputation, or diversion of the contents of the originating viscera are beneficial. Otherwise, local care of the affected skin will often require creative efforts. Sometimes a *de facto* stoma can be created.

Extensive malignant ulcerations pose another dramatic nursing challenge. The goals should be to reduce cosmetic distress, to keep the lesion clean and odor-free, and to avoid serious infection or hemorrhage. There is no substitute for gentle, thorough cleansing and dressing, usually twice a day. Half-strength hydrogen peroxide or Dakin's solution seem to be well tolerated and mildly bactericidal. If odor is a problem, powdered tetracycline (from a capsule) is quite effective when sprinkled over the lesions before dressing. If minor bleeding occurs, pressure, gelfoam, or powdered thrombin may help. Suture material should be available for efforts to tie major middle-size arteries that bleed, though rupture of a major artery is often best managed with an abundance of towels,[47] since repair or ligature is so likely doomed and the patient is so rapidly unconscious. If the patient is frightened, parenteral morphine, hyoscine, or diazepam (Valium) will provide rapid tranquilization and also fairly reliable amnesia if the patient survives.[48] Some attention should be given to making all dressings cosmetically acceptable, especially on the neck, face, and hands. Creative application of dressings can mask the absence or distortion of cheek, jaw, or eye, and thereby keep it easier for visitors to see the patient, and for the patient to see a mirror.

Pruritus. The itching associated with malignancy usually has no definite treatable origin. Pruritus of biliary obstruction sometimes responds to cholestyramine (Questran). Some pruritus is caused by drugs, soaps and lotions, or other allergens. If no specific cause can be remedied, antihistamines such as hydroxyzine (Vistaril), phenothiazines such as trimeprazine (Temaril), or topical or systemic steriods may be of some help.[49] Relief is reported to last a day or two after intravenous

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[47] "[The patient at risk of hemorrhage] should be encouraged to pursue his normal activities. It is, however, kind to arrange for the traditional red blanket to be draped about him to lessen the distress of any onlookers if a large bleed ensues." Williams, *supra* note 36, at 137.

[48] Cicely Saunders, *Principles of Symptom Control in Terminal Care*, in Marcus Reidenberg, ed., *Clinical Pharmacology of Symptom Control*, 66 The Medical Clinics of North America 1169, 1178 (1982).

[49] *Id.* at 1177; Richard K. Winkelmann, *Pharmacologic Control of Pruritus*, in Marcus Reidenberg, ed., in *Clinical Pharmacology of Symptom Control*, 66 The Medical Clinics of North America 1119 (1982).

use of local anesthetics.[50]

Fever. History and physical exam are especially helpful in distinguishing among the very different possible etiologies of fever—especially dehydration, constipation, central nervous system lesions, urinary infection, or pneumonia. The causative etiology can generally be treated. Furthermore, usually the patient benefits from antipyretics, increased fluid intake (if possible), and alcohol sponge baths. If the fever probably results from an overwhelming bacterial infection, with falling blood pressure and obtundation, treatment may appropriately be withheld, including not giving antibiotics, intravenous volume expansion, or pressors. Symptomatic urinary tract infection rarely is overwhelming but can be quite distressing, thus nearly always warranting antibiotic therapy.[51]

Weakness. Most dying people feel weak; oddly, many people need to be reassured that weakness is acceptable. Appropriate use of antidepressants and pain control drugs sometimes helps to ameliorate weakness. Transfusions for profound anemia are sometimes dramatically beneficial. Steroid effects, uremia, hepatic encephalopathy, hypercarbia, and hypoxia are often partially treatable. Anabolic hormones like nandrolone decanoate (Deca-Durabolin) or fluoxymesterone (Halotestin) or adrenocortical steriods like prednisone or dexamethasone (Decadron) are sometimes beneficial. Central nervous system stimulants like methylphenidate (Ritalin) have been reported to benefit a few patients, but the incidence of confusion is fairly high.[52]

Respiratory Symptoms. Few symptom groups are so frustrating as hiccups, cough, and dyspnea. Patients with serious disease rarely respond to the "first-aid" measures to stop hiccups. Amphetamines, phenothiazines, haloperidol, or metoclopramide sometimes work.[53] Phrenic nerve block is usually effective but sometimes fails and always compromises respiratory reserve.

Coughing might arise from treatable causes—pleural effusion, pulmonary embolus, dehydration of the bronchi, pneumonia, or thick sputum. Often, however, humidifiers, potassium iodide, chest physical therapy, and other remedial measures do not help. Cough might be suppressed by terpin hydrate with codeine, hycodan, or with stronger narcotics. Using viscous

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[50] H.U. Gerbershagen, in SYMPOSIUM ON PAIN, *supra* note 1, at 301-02; Luis Tapia *et al., Pruritus in Dialysis Patients Treated with Parenteral Lidocaine*, 296 NEW ENG. J. MED. 261 (1977).

[51] Zimmerman, *supra* note 10, at 73.

[52] *Id.* at 67-68; Twycross, *supra* note 2, at 80-81.

[53] Baines, *supra* note 29, at 106; Zimmerman, *supra* note 10, at 73.

lidocaine (Xylocaine) and other local anesthetics as a gargle or sucking on hard candies may help for a short time.[54]

Whether or not to treat pneumonia with antibiotics depends upon the patient's situation.[55] Pneumonia may sometimes be the "old man's friend," as it is often called, and could well be acceptable, with cough and dyspnea controlled by morphine. Sometimes, though, even in a patient expected to die soon, antibiotics, chest physical therapy, and oxygen are better.

No symptom is so terrifying as dyspnea. Usually any remediable cause—pleural fluid, congestive heart failure, anemia, and bronchospasm, for example—should be sought.[56] Positioning the patient in a semirecumbent position, blowing cool air over his or her face, and judicious use of oxygen often help. Radiation to the mediastinum and dexamethasone (4 mg. every 6 hours) may help if the etiology is mediastinal tumor. Even if pain is not a problem, low-dose narcotics help, either by reducing anxiety, by reducing pulmonary vasocongestion, or by dulling the medullary reflexes.[57] A few milligrams of morphine every 3-4 hours or about 5 mg. at bedtime can greatly add to the patient's comfort without causing any deleterious effect on respiratory effort. Dyspnea as a terminal event is discussed in the next section. When a dying patient is on a respirator, rather rapid and controlled weaning is sometimes indicated; such weaning should proceed with symptom control but without trying to maintain respiratory function.[58]

Agonal symptoms. The symptoms discussed thus far generally apply to patients who are within a few months of death. Sometimes the last few hours and minutes present some additional symptoms that can be treated.

Agonal respiratory insufficiency. No death is more agonizing for the aware patient and all around him or her than one from respiratory insufficiency. Untreated, the patient will struggle for air until exhausted, when carbon dioxide narcosis and progressive hypoxia finally bring death fairly quickly. The patient must sit, can barely speak, and can continue in this way for hours or even a few days. In this situation, the care giver must be certain that no specific remedy—diuretics,

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[54] Zimmerman, *supra* note 10, at 72-73.

[55] Baines, *supra* note 29, at 108-09.

[56] However, in discussing bronchial carcinoma, some advocate not using thoracentesis or intrapleural cytotoxic agents but instead relying upon morphine for dyspnea. *See* Bates and Vanier, *supra* note 1, at 132.

[57] Twycross, *supra* note 2, at 79.

[58] Ake Grenvik, *Terminal Weaning: Discontinuance of Life-Supporting Therapy in the Terminally Ill Patient* (Editorial), 11 Crit. Care Med. (forthcoming, May 1983).

oxygen, thoracentesis, and so on—is warranted to relieve the respiratory insufficiency.[59] Then, with the appropriate consent by the patient and family, morphine can be given intramuscularly in small doses (for a patient who has not developed any tolerance, 3-5 mg. in each dose) every 15-20 minutes until some relief is obtained. Usually, the patient's breathing will slow slightly and become a little deeper and his or her terror will subside. No more morphine may be needed. If the patient is already quite exhausted, the slowed respirations will induce hypercapnia, which will perpetuate the sedation and the patient will die in the ensuing sleep. If the patient has more reserve, the severe dyspnea will probably recur, and can again be treated with morphine. Although this approach is far from perfect, it does allow the physician to improve upon what is otherwise a singularly terrifying and agonizing final few hours.

Aesthetic considerations. Even when a patient is beyond caring about how others remember his or her last hours, this period can have serious effects on family, friends, and care givers. Usually it is important to keep the "death bed" as aesthetic as possible. This entails considering the sensory impressions presented by the patient and surroundings.

The visual impression should, as far as possible, be one of peace and privacy. Attentive nursing can minimize disruption caused by emesis or bleeding. Agonal seizures or muscle twitches are usually minor and brief, but respond to intramuscular diazepam (Valium) if needed. Emaciation, artificial tubes, and various wounds can be disguised with skillful use of sheets and bedspreads.

Masking unpleasant odors by putting extra sheets over wounds and incontinence, ensuring good air circulation, and using pleasant odors helps family members to stay with the patient.

Some patients develop a noisy bronchial congestion or relaxation of the soft tissues shortly before death—the well-known "death rattle." If this is distressing to the family (it never seems to be present in patients awake enough to be distressed by it), scopolamine or atropine (0.4 mg. of either by injection), added to a narcotic, is usually sufficient to make the patient sound better.[60]

Patients, care givers, and family members seem to benefit from maintaining physical contact as the end of life nears. Family members may need to be asked if they would like to hold the patient's hand or wipe the forehead, as they are commonly uncertain about what they can or should do.

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[59] Baines, *supra* note 29, at 109-10; Saunders, *supra* note 48, at 1175-76.
[60] Baines *supra* note 29, at 110.

Bereavement

The responsibilities of those who cared for the patient who died do not end with that person's death. It is well known that the death of a loved one is a stressful event that can lead to premature death, increased morbidity, and psychological difficulties for survivors.[61] Health care professionals who cared for the patient will often have come to know that person's family during the patient's illness. They are therefore well situated to observe behavior patterns, emotional reactions, and social circumstances that may signal difficulty during bereavement.

Although the majority of people grieve "normally" and return to adequate levels of functioning within a reasonable period, many people need support during bereavement and some people (variously estimated at 10-20%) will be unable to resolve their grief on their own and will benefit from professional help. Research has shown that people who lack social supports, whose relationships with the deceased involved ambivalent feelings, who suffered a completely unexpected loss, or who have preexisting physical or psychological disorders are at high risk for pathological grief.[62] Furthermore, the circumstances surrounding the death itself and the particular person who dies may render the survivors especially vulnerable. The death of a child, for example, is generally extremely stressful for parents and siblings and is likely to require special attention. Health professionals are likely to learn of these circumstances while they are caring for the patient, which should trigger the professionals' attention later to signs that the survivors are encountering difficulties that may warrent help.

Although the health care professionals who cared for the patient need not also assume full responsibility for the care of survivors, it is their responsibility to be aware of signs of

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[61] *See e.g.*, T.H. Holmes and R.H. Rake, *The Social Readjustment Rating Scale*, 11 J. Psychosomatic Res. 213 (1967); K.J. Helsing and M. Szklo, *Mortality After Bereavement*, 114 Am. J. Epidemiology 41 (1981); C.M. Parkes and R. Brown, *Health After Bereavement: A Controlled Study of Young Boston Widows and Widowers*, 34 Psychosomatic Med. 449 (1972); G.L. Klerman and J.E. Izen, *The Effects of Bereavement and Grief on Physical Health and General Well-Being*, 9 Advances in Psychosomatic Med. 1, 41 (1977).

[62] Beverly Raphael, *Preventive Intervention with the Recently Bereaved*, 34 Archives Gen. Psychiatry 1450 (1977); Robert S. Weiss, *Recovery from Bereavement: Findings and Issues*, presented at NIH Professional Conference, Nov. 1982, at 6 (summary of findings in Colin Murray Parkes and Robert S. Weiss, Recovery from Bereavement, Basic Books, New York (in press)); Mary L.S. Vachon *et al., Predictors and Correlates of Adaption to Conjugal Bereavement*, 139 Am. J. Psychiatry 998 (1982); Paula J. Clayton, *Bereavement and its Management*, in E.S. Paykel, ed., Handbook of Affective Disorders, Churchill Livingstone, Edinburgh (1982) at Chapter 31.

pathologic grief, to have enough contact with survivors to detect the need for further help, and to be knowledgeable about community resources and professional services, so they can refer survivors to these resources if needed. In addition, part of the role of health care professionals and institutions is to respect, insofar as possible, the needs of a culturally and religiously diverse population. This means seeking out and respecting the family's wishes with regard to autopsy, disposition of the body, and possible funeral arrangements.

This Appendix was prepared by the Commission's Assistant Director for Medical Studies, Joanne Lynn, M.D., who wishes to acknowledge the helpful reviews and advice of several commissioners, of Drs. William T. Beaver, Paul Beeson, Raymond Houde, Fred Plum, Cicely Saunders, Thomas Walsh and Jack M. Zimmerman, and of the nursing staff of the Washington Home Hospice. Similar material is to be published in John R. Walsh and Christine K. Cassel, eds., GERIATRIC MEDICINE: PRINCIPLES AND PRACTICES, Springer-Verlag, New York (1983).

Statements by the AMA and the Catholic Church

C

Judicial Council, American Medical Association*

§ 2.10 Quality of Life.

In the making of decisions for the treatment of seriously deformed newborns or persons who are severely deteriorated victims of injury, illness or advanced age, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life is a factor to be considered in determining what is best for the individual. Life should be cherished despite disabilities and handicaps, except when prolongation would be inhumane and unconscionable. Under these circumstances, withholding or removing life supporting means is ethical provided that the normal care given an individual who is ill is not discontinued.

In desperate situations involving newborns, the advice and judgment of the physician should be readily available, but the decision whether to exert maximal efforts to sustain life should be the choice of the parents. The parents should be told the options, expected benefits, risks and limits of any proposed care; how the potential for human relationships is affected by the infant's condition; and relevant information and answers to their questions. The presumption is that the love which parents usually have for their children will be dominant in the decisions which they make in determining what is in the best interest of their children. It is to be expected that parents will

* Selections from OPINIONS OF THE JUDICIAL COUNCIL OF THE AMERICAN MEDICAL ASSOCIATION, Dr. John H. Burkhart, Chairman, American Medical Association, Chicago (1982) at 9-10.

act unselfishly, particularly where life itself is at stake. Unless there is convincing evidence to the contrary, parental authority should be respected.

§ 2.11 Terminal Illness.

The social commitment of the physician is to prolong life and relieve suffering. Where the observance of one conflicts with the other, the physician, patient, and/or family of the patient have discretion to resolve the conflict.

For humane reasons, with informed consent a physician may do what is medically necessary to alleviate severe pain, or cease or omit treatment to let a terminally ill patient die, but he should not intentionally cause death. In determining whether the administration of potentially life-prolonging medical treatment is in the best interest of the patient, the physician should consider what the possibility is for extending life under humane and comfortable conditions and what are the wishes and attitudes of the family or those who have responsibility for the custody of the patient.

Where a terminally ill patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis, all means of life support may be discontinued. If death does not occur when life support systems are discontinued, the comfort and dignity of the patient should be maintained.

Declaration on Euthanasia, the Sacred Congregation for the Doctrine of the Faith*

Introduction

The rights and values pertaining to the human person occupy an important place among the questions discussed today. In this regard, the Second Vatican Ecumenical Council solemnly reaffirmed the lofty dignity of the human person, and in a special way his or her right to life. The Council therefore condemned crimes against life "such as any type of murder, genocide, abortion, euthanasia, or wilful suicide" (Pastoral Constitution *Gaudium et Spes*, 27).

More recently, the Sacred Congregation for the Doctrine of the Faith has reminded all the faithful of Catholic teaching on procured abortion.[1] The Congregation now considers it opportune to set forth the Church's teaching on euthanasia.

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* Vatican City (May 5, 1980).

[1] *Declaration on Procured Abortion*, 18 November 1974: AAS 66 (1974), pp. 730-747.

It is indeed true that, in this sphere of teaching, the recent Popes have explained the principles, and these retain their full force;[2] but the progress of medical science in recent years has brought to the fore new aspects of the question of euthanasia, and these aspects call for further elucidation on the ethical level.

In modern society, in which even the fundamental values of human life are often called into question, cultural change exercises an influence upon the way of looking at suffering and death; moreover, medicine has increased its capacity to cure and to prolong life in particular circumstances, which sometimes give rise to moral problems. Thus people living in this situation experience no little anxiety about the meaning of advanced old age and death. They also begin to wonder whether they have the right to obtain for themselves or their fellowmen an "easy death", which would shorten suffering and which seems to them more in harmony with human dignity.

A number of Episcopal Conferences have raised questions on this subject with the Sacred Congregation for the Doctrine of the Faith. The Congregation, having sought the opinion of experts on the various aspects of euthanasia, now wishes to respond to the Bishops' questions with the present Declaration, in order to help them to give correct teaching to the faithful entrusted to their care, and to offer them elements for reflection that they can present to the civil authorities with regard to this very serious matter.

The considerations set forth in the present document concern in the first place all those who place their faith and hope in Christ, who, through his life, death and Resurrection, has given a new meaning to existence and especially to the death of the Christian, as Saint Paul says: "If we live, we live to the Lord, and if we die, we die to the Lord" (*Rom* 14:8; cf. *Phil* 1:20).

As for those who profess other religions, many will agree with us that faith in God the Creator, Provider and Lord of

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[2] Pius XII, *Address to those attending the Congress of the International Union of Catholic Women's Leagues*, 11 September 1947: AAS 39 (1947), p. 483; *Address to the Italian Catholic Union of Midwives*, 29 October 1951: AAS 43 (1951), pp. 835-854; *Speech to the members of the International Office of military medicine documentation*, 19 October 1953: AAS 45 (1953), pp. 744-754; *Address to those taking part in the IXth Congress of the Italian Anaesthesiological Society*, 24 February 1957: AAS 49 (1957), p. 146; cf. also *Address on "reanimation,"* 24 November 1957: AAS 49 (1957), pp. 1027-1033; Paul VI, *Address to the members of the United Nations Special Committee on Apartheid*, 22 May 1974: AAS 66 (1974), p. 346; John Paul II: *Address to the Bishops of the United States of America*, 5 October 1979: AAS 71 (1979), p. 1225.

life—if they share this belief—confers a lofty dignity upon every human person and guarantees respect for him or her.

It is hoped that this Declaration will meet with the approval of many people of good will, who, philosophical or ideological differences notwithstanding, have nevertheless a lively awareness of the rights of the human person. These rights have often in fact been proclaimed in recent years through declarations issued by International Congresses;[3] and since it is a question here of fundamental rights inherent in every human person, it is obviously wrong to have recourse to arguments from political pluralism or religious freedom in order to deny the universal value of those rights.

The Value Of Human Life

Human life is the basis of all goods, and is the necessary source and condition of every human activity and of all society. Most people regard life as something sacred and hold that no one may dispose of it at will, but believers see in life something greater, namely a gift of God's love, which they are called upon to preserve and make fruitful. And it is this latter consideration that gives rise to the following consequences:

1. No one can make an attempt on the life of an innocent person without opposing God's love for that person, without violating a fundamental right, and therefore without committing a crime of the utmost gravity.[4]

2. Everyone has the duty to lead his or her life in accordance with God's plan. That life is entrusted to the individual as a good that must bear fruit already here on earth, but that finds its full perfection only in eternal life.

3. Intentionally causing one's own death, or suicide, is therefore equally as wrong as murder; such an action on the part of a person is to be considered as a rejection of God's sovereignty and loving plan. Furthermore, suicide is also often a refusal of love for self, the denial of the natural instinct to live, a flight from the duties of justice and charity owed to one's neighbour, to various communities or to the whole of society—although, as is generally recognized, at times there are psychological factors present that can diminish responsibility or even completely remove it.

However, one must clearly distinguish suicide from that sacrifice of one's life whereby for a higher cause, such as God's glory, the salvation of souls or the service of one's brethren, a

[3] One thinks especially of Recommendation 779 (1976) on the rights of the sick and dying, of the Parliamentary Assembly of the Council of Europe at its XXVIIth Ordinary Session, cf. Sipeca, No. 1, March 1977, pp. 14-15.

[4] We leave aside completely the problems of the death penalty and of war, which involve specific considerations that do not concern the present subject.

person offers his or her own life or puts it in danger (cf. *Jn* 15:14).

Euthanasia

In order that the question of euthanasia can be properly dealt with, it is first necessary to define the words used.

Etymologically speaking, in ancient times *euthanasia* meant an *easy death* without severe suffering. Today one no longer thinks of this original meaning of the word, but rather of some intervention of medicine whereby the sufferings of sickness or of the final agony are reduced, sometimes also with the danger of suppressing life prematurely. Ultimately, the word *euthanasia* is used in a more particular sense to mean "mercy killing", for the purpose of putting an end to extreme suffering, or saving abnormal babies, the mentally ill or the incurably sick from the prolongation, perhaps for many years, of a miserable life, which could impose too heavy a burden on their families or on society.

It is therefore necessary to state clearly in what sense the word is used in the present document.

By euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia's terms of reference, therefore, are to be found in the intention of the will and in the methods used.

It is necessary to state firmly once more that nothing and no one can in any way permit the killing of an innocent human being, whether a foetus or an embryo, an infant or an adult, an old person, or one suffering from an incurable disease, or a person who is dying. Furthermore, no one is permitted to ask for this act of killing, either for himself or herself or for another person entrusted to his or her care, nor can he or she consent to it, either explicitly or implicitly. Nor can any authority legitimately recommend or permit such an action. For it is a question of the violation of the divine law, an offence against the dignity of the human person, a crime against life, and an attack on humanity.

It may happen that, by reason of prolonged and barely tolerable pain, for deeply personal or other reasons, people may be led to believe that they can legitimately ask for death or obtain it for others. Although in these cases the guilt of the individual may be reduced or completely absent, nevertheless the error of judgment into which the conscience falls, perhaps in good faith, does not change the nature of this act of killing, which will always be in itself something to be rejected. The pleas of gravely ill people who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact it is almost always a case of an anguished plea for help and love. What a sick person needs, besides medical care, is love, the human and supernatural warmth with which the sick

person can and ought to be surrounded by all those close to him or her, parents and children, doctors and nurses.

The Meaning of Suffering for Christians and the Use of Painkillers

Death does not always come in dramatic circumstances after barely tolerable sufferings. Nor do we have to think only of extreme cases. Numerous testimonies which confirm one another lead one to the conclusion that nature itself has made provision to render more bearable at the moment of death separations that would be terribly painful to a person in full health. Hence it is that a prolonged illness, advanced old age, or a state of loneliness or neglect can bring about psychological conditions that facilitate the acceptance of death.

Nevertheless the fact remains that death, often preceded or accompanied by severe and prolonged suffering, is something which naturally causes people anguish.

Physical suffering is certainly an unavoidable element of the human condition; on the biological level, it constitutes a warning of which no one denies the usefulness; but, since it affects the human psychological makeup, it often exceeds its own biological usefulness and so can become so severe as to cause the desire to remove it at any cost.

According to Christian teaching, however, suffering, especially suffering during the last moments of life, has a special place in God's saving plan; it is in fact a sharing in Christ's Passion and a union with the redeeming sacrifice which he offered in obedience to the Father's will. Therefore one must not be surprised if some Christians prefer to moderate their use of painkillers, in order to accept voluntarily at least a part of their sufferings and thus associate themselves in a conscious way with the sufferings of Christ crucified (cf. *Mt* 27:34). Nevertheless it would be imprudent to impose a heroic way of acting as a general rule. On the contrary, human and Christian prudence suggest for the majority of sick people the use of medicines capable of alleviating or suppressing pain, even though these may cause as a secondary effect semiconsciousness and reduced lucidity. As for those who are not in a state to express themselves, one can reasonably presume that they wish to take these painkillers, and have them administered according to the doctor's advice.

But the intensive use of painkillers is not without difficulties, because the phenomenon of habituation generally makes it necessary to increase their dosage in order to maintain their efficacy. At this point it is fitting to recall a declaration by Pius XII, which retains its full force; in answer to a group of doctors who had put the question: "Is the suppression of pain and consciousness by the use of narcotics...permitted by religion and morality to the doctor and the patient (even at the approach of death and if one foresees that the use of narcotics

will shorten life)?", the Pope said: "If no other means exist, and if, in the given circumstances, this does not prevent the carrying out of other religious and moral duties: Yes".[5] In this case, of course, death is in no way intended or sought, even if the risk of it is reasonably taken; the intention is simply to relieve pain effectively, using for this purpose painkillers available to medicine.

However, painkillers that cause unconsciousness need special consideration. For a person not only has to be able to satisfy his or her moral duties and family obligations; he or she also has to prepare himself or herself with full consciousness for meeting Christ. Thus Pius XII warns: "It is not right to deprive the dying person of consciousness without a serious reason".[6]

Due Proportion in the Use of Remedies

Today it is very important to protect, at the moment of death, both the dignity of the human person and the Christian concept of life, against a technological attitude that threatens to become an abuse. Thus, some people speak of a "right to die", which is an expression that does not mean the right to procure death either by one's own hand or by means of someone else, as one pleases, but rather the right to die peacefully with human and Christian dignity. From this point of view, the use of thereapeutic means can sometimes pose problems.

In numerous cases, the complexity of the situation can be such as to cause doubts about the way ethical principles should be applied. In the final analysis, it pertains to the conscience either of the sick person, or of those qualified to speak in the sick person's name, or of the doctors, to decide, in the light of moral obligations and of the various aspects of the case.

Everyone has the duty to care for his or her own health or to seek such care from others. Those whose task it is to care for the sick must do so conscientiously and administer the remedies that seem necessary or useful.

However, is it necessary in all circumstnaces to have recourse to all possible remedies?

In the past, moralists replied that one is never obliged to use "extraordinary" means. This reply which as a principle still holds good, is perhaps less clear today, by reason of the imprecision of the term and the rapid progress made in the treatment of sickness. Thus some people prefer to speak of "proportionate" and "disproportionate" means. In any case, it will be possible to make a correct judgment as to the means by

[5] Pius XII, *Address* of 24 February 1957; AAS 49 (1957), p. 147.
[6] Pius XII, *ibid.*, p. 145; cf. *Address* of 9 September 1958: AAS 50 (1958), p. 694.

studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources.

In order to facilitate the application of these general principles, the following clarifications can be added:

If there are no other sufficient remedies, it is permitted, with the patient's consent, to have recourse to the means provided by the most advanced medical techniques, even if these means are still at the experimental stage and are not without a certain risk. By accepting them, the patient can even show generosity in the service of humanity.

It is also permitted, with the patient's consent, to interrupt these means, where the results fall short of expectations. But for such a decision to be made, account will have to be taken of the reasonable wishes of the patient and the patient's family, as also of the advice of the doctors who are specially competent in the matter. The latter may in particular judge that the investment in instruments and personnel is disproportionate the the results foreseen; they may also judge that the techniques applied impose on the patient strain or suffering out of proportion with the benefits which he or she may gain from such techniques.

It is also permissible to make do with the normal means that medicine can offer. Therefore one cannot impose on anyone the obligation to have recourse to a technique which is already in use but which carries a risk or is burdensome. Such a refusal is not the equivalent of suicide; on the contrary, it should be considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expense on the family or the community.

When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted. In such circumstances the doctor has no reason to reproach himself with failing to help the person in danger.

Conclusion

The norms contained in the present Declaration are inspired by a profound desire to serve people in accordance with the plan of the Creator. Life is a gift of God, and on the other hand death is unavoidable; it is necessary therefore that we, without in any way hastening the hour of death, should be able to accept it with full responsibility and dignity. It is true that death marks the end of our earthly existence, but at the

same time it opens the door to immortal life. Therefore all must prepare themselves for this event in the light of human values, and Christians even more so in the light of faith.

As for those who work in the medical profession, they ought to neglect no means of making all their skill available to the sick and the dying; but they should also remember how much more necessary it is to provide them with the comfort of boundless kindness and heartfelt charity. Such service to people is also service to Christ the Lord, who said: "As you did it to one of the least of these my brethren, you did it to me" (*Mt* 25:40).

At the audience granted to the undersigned Prefect, His Holiness Pope John Paul II approved this Declaration, adopted at the ordinary meeting of the Sacred Congregation for the Doctrine of the Faith, and ordered its publication.

Rome, the Sacred Congregation for the Doctrine of the Faith, 5 May 1980.

Franjo Card. Seper
Prefect

Jerome Hamer, O.P.
Tit. Archbishop of Lorium
Secretary

Natural Death Statutes and Proposals

D

Comparison of Existing Natural Death Statutes 310

Medical Treatment Decision Act (Model Bill) 313

Natural Death Statutes, by State (alphabetically) 318

Table D1:

Comparison of Existing Natural Death Statutes*

	Ala.	Ark.	Calif.	Del.	D.C.	Id.
Is directive† limited to patients who will die very soon even with treatment?	yes	no	yes	yes	yes	yes
May form of directive be varied?	yes	yes	no	yes	yes	no
May proxy be named in directive?	possibly	possibly	no	yes	possibly	no
May directive be written for a child or an incompetent adult?	no	yes	no	no	no	no
Is directive said to be nullified by pregnancy?	yes	no	yes	yes	no	no
Are penalties specified for physicians who refuse to follow a directive?	no	no	yes	no	yes	no
Does the statute specify that the physician must inform the patient (if competent) of the terminal prognosis before the directive is binding?	no	no	yes	no	yes(2)	yes
Is directive binding only if patient knows of terminal condition?	no	no	yes	no	(3)	no
Is a waiting period imposed after patient is informed before directive is binding?	no	no	yes	no	no	no
Must a directive be periodically reaffirmed?	no	no	yes	yes	no	yes
Must terminal conditions be confirmed by consultation and certified in writing?	yes	no(1)	yes	yes	yes	no

for footnotes, see p. 312.

Ks.	Nev.	N.M.	N.C.	Ore.	Tx.	Vt.	Va.(10)	Wash.
yes	uncertain	yes	no	yes	yes	yes	no(11)	yes
yes	no(5)	yes	yes	no	no	yes	yes(12)	yes
possibly	no	possibly	possibly	no	no	possibly	possibly	possibly
no	no	for child	yes(6)	no	no	no	no(13)	no
yes	yes	no	no	no	yes	no	no	yes
yes	no	no	no	yes	yes	no(9)	no	no(9)
no(4)	no	no	no	yes	no(4)	no	no	no(4)
no	no	no	no	yes	(8)	no	no	(15)
no	no	no	no	yes	no	no	no	no
no	no	no	no	yes	no	no	no	no
yes	no	yes	yes(7)	yes(7)	yes	no	yes(14)	yes

* A natural death statute is one that establishes a way for patients while competent to direct that treatment at the end of their lives, if they are not then able to make decisions, shall not include artificial interventions that prolong dying. The individual state statutes are given *infra* at pp. 318-87.

† "Directive" means the written instrument implementing a natural death statute for a particular patient.

(1) Except, a directive may be made by legally appointed guardian on behalf of an incompetent adult.

(2) The physician probably is given an affirmative duty to inform all patients whose directives thereby become binding.

(3) If patient is able to comprehend, then directive is binding only if patient is informed. If patient is unable to comprehend, directive is binding when terminal condition is certified.

(4) Except that the desires of a qualified patient at the time are always governing, and the patient probably must be informed if the desires are to have this force.

(5) Must be "substantially" the form given in the statute.

(6) Procedures are specified for comatose incompetent patients.

(7) Does not specify written certification.

(8) Directive is binding only if patient is "qualified" at the time it is executed. The statute does not state that informing a competent patient is essential to qualifying, but it would be reasonable to interpret the statute as entailing this requirement.

(9) Statute specified that physician has a duty to inform the patient or actively assist in selecting another physician but does not specify penalties for failure to do so.

(10) The Virginia statute was passed by both houses and awaiting the governor's signature as of March 17, 1983.

(11) The definition of terminal condition requires that death be imminent, but does not specify whether it must be imminent even with the proposed treatment.

(12) Directive may be made orally if done after diagnosis of terminal condition.

(13) A procedure is given for foregoing life-sustaining procedures on behalf of adult incompetent patients.

(14) Where patient is competent, certification need only be made by the attending physician.

(15) If patient is competent, the statute's requirement that the decision be reaffirmed would seem to entail assuring that the patient knows the terminal prognosis.

Medical Treatment Decision Act* (Model Bill)

*The following Model Bill was drafted at Yale Law School in a Legislative Services Project sponsored by the Society for the Right to Die. The use of * and ** is to indicate alternatives.*

1. Purpose

The Legislature finds that adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of a terminal condition.

In order that the rights of patients may be respected even after they are no longer able to participate actively in decisions about themselves, the Legislature hereby declares that the laws of the State of _____ shall recognize the right of an adult person to make a written declaration instructing his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition.

2. Definitions

The following definitions shall govern the construction of this act:

(a) "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(b) "Declaration" means a witnessed document in writing, voluntarily executed by the declarant in accordance with the requirements of Section 3 of this act.

(c) "Life-sustaining procedure" means any medical procedure or intervention which, when applied to a qualified patient, would serve only to prolong the dying process and where, in the judgment of the attending physician, death will occur whether or not such procedures are utilized. "Life-sustaining procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to provide comfort care.

(d) "Qualified patient" means a patient who has executed a declaration in accordance with this act and who has been diagnosed and certified in writing to be afflicted with a terminal condition by two physicians who have personally examined the patient, one of whom shall be the attending physician.

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* From *Handbook of Enacted Laws*, published by the Society for the Right to Die, 250 West 57th Street, New York, N.Y. 10107. Reprinted by permission.

3. Execution of Declaration

Any adult person may execute a declaration directing the withholding or withdrawal of life-sustaining procedures in a terminal condition. The declaration shall be signed by the declarant in the presence of two subscribing witnesses *(who are not) **(no more than one of whom may be) (a) related to the declarant by blood or marriage, (b) entitled to any portion of the estate of the declarant under any will of declarant or codicil thereto then existing or, at the time of the declaration, by operation of law then existing, (c) a claimant against any portion of the estate of the declarant, or (d) directly financially responsible for the declarant's medical care.

It shall be the responsibility of declarant to provide for notification to his attending physician of the existence of the declaration. An attending physician who is so notified shall make the declaration, or a copy of the declaration, a part of the declarant's medical records.

The declaration shall be substantially in the following form, but in addition may include other specific directions. Should any of the other specific directions be held to be invalid, such invalidity shall not affect other directions of the declaration which can be given effect without the invalid direction, and to this end the directions in the declaration are severable.

DECLARATION

Declaration made this _____ day of _____ (month, year). I, _____, being of sound mind, willfully and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care.

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this declaration shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

Signed _____

City, County and State of Residence

_____

The declarant has been personally known to me and I believe him or her to be of sound mind.

Witness _____

Witness _____

4. Revocation

A declaration may be revoked at any time by the declarant, without regard to his or her mental state or competency, by any of the following methods:

(a) By being canceled, defaced, obliterated, or burnt, torn, or otherwise destroyed by the declarant or by some person in his or her presence and by his or her direction.

(b) By a written revocation of the declarant expressing his or her intent to revoke, signed and dated by the declarant. The attending physician shall record in the patient's medical record the time and date when he or she received notification of the written revocation.

(c) By a verbal expression by the declarant of his or her intent to revoke the declaration. Such revocation shall become effective upon communication to the attending physician by the declarant or by a person who is reasonably believed to be acting on behalf of the declarant. The attending physician shall record in the patient's medical record the time, date and place of the revocation and the time, date and place, if different, of when he or she received notification of the revocation.

5. Physician's Responsibility: Written Certification

An attending physician who has been notified of the existence of a declaration executed under this act shall, without delay after the diagnosis of a terminal condition of the declarant, take the necessary steps to provide for written certification and confirmation of the declarant's terminal condition, so that declarant may be deemed to be a qualified patient, as defined in Section 1(d) of this act.

An attending physician who fails to comply with this section shall be deemed to have refused to comply with the declaration and shall be liable as specified in Section 7(a).

6. Physician's Responsibility and Immunities

The desires of a qualified patient who is competent shall at all times supersede the effect of the declaration.

If the qualified patient is incompetent at the time of the decision to withhold or withdraw life-sustaining procedures, a declaration executed in accordance with Section 3 of this act is presumed to be valid. For the purpose of this act, a physician or health care facility may presume in the absence of actual

notice to the contrary that an individual who executed a declaration was of sound mind when it was executed. The fact of an individual's having executed a declaration shall not be considered as an indication of a declarant's mental incompetency. *(Age of itself shall not be a bar to a determination of competency.)

In the absence of actual notice of the revocation of the declaration, none of the following, when acting in accordance with the requirements of this act, shall be subject to civil liability therefrom, unless negligent, or shall be guilty of any criminal act or of unprofessional conduct:

(a) A physician or health facility which causes the withholding or withdrawal of life-sustaining procedures from a qualified patient.

(b) A licensed health professional, acting under the direction of a physician, who participates in the withholding or withdrawal of life-sustaining procedures.

7. Penalties

(a) An attending physician who refuses to comply with the declaration of a qualified patient pursuant to this act shall make the necessary arrangements to effect the transfer of the qualified patient to another physician who will effectuate the declaration of the qualified patient. An attending physician who fails to comply with the declaration of a qualified patient or to make the necessary arrangements to effect the transfer shall be civilly liable.

(b) Any person who willfully conceals, cancels, defaces, obliterates, or damages the declaration of another without such declarant's consent or who falsifies or forges a revocation of the declaration of another shall be civilly liable.

(c) Any person who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of a revocation as provided in Section 4, with the intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarant, and thereby, because of such act, directly causes life-sustaining procedures to be withheld or withdrawn and death to thereby be hastened, shall be subject to prosecution for unlawful homicide.

8. General Provisions

(a) The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of this act shall not, for any purpose, constitute a suicide.

(b) The making of a declaration pursuant to Section 3 shall not affect in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining

procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) No physician, health facility, or other health provider, and no health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or non-profit hospital plan, shall require any person to execute a declaration as a condition for being insured for, or receiving, health care services.

(d) Nothing in this act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this act are cumulative.

(e) This act shall create no presumption concerning the intention of an individual who has not executed a declaration to consent to the use or withholding of life-sustaining procedures in the event of a terminal condition.

(f) If any provision of this act or the application thereof to any person or circumstances is held invalid, such invalidity shall not affect other provisions or applications of the act which can be given effect without the invalid provision or application, and to this end the provisions of this act are severable.

Natural Death Statutes, by State*

Alabama

§§ 22-8A-1. Short title.

This chapter shall be known and may be cited as the "Natural Death Act."

§ 22-8A-2. Legislative intent.

The legislature finds that adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of a terminal condition.

In order that the rights of patients may be respected even after they are no longer able to participate actively in decisions about themselves, the legislature hereby declares that the laws of this state shall recognize the right of an adult person to make a written declaration instructing his or her physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition.

§ 22-8A-3. Definitions.

As used in this chapter, the following terms shall have the following meanings, respectively, unless the context clearly indicates otherwise:

(1) Attending physician. The physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(2) Declaration. A witnessed document in writing, voluntarily executed by the declarant in accordance with the requirements of section 22-8A-4.

(3) Life-sustaining procedure. Any medical procedure or intervention which, when applied to a qualified patient, would serve only to prolong the dying process and where, in the judgment of the attending physician, death will occur whether or not such procedure or intervention is utilized. Life-sustaining procedure shall not include the administration of medication or the performance of any medical procedure deemed necessary to provide comfort or care or to alleviate pain.

(4) Physician. A person licensed to practice medicine and osteopathy in the state of Alabama.

(5) Qualified patient. A patient, who has executed a declaration in accordance with this chapter and who has been diagnosed and certified in writing to be afflicted with a terminal condition by two physicians who have personally

* Statutes have been edited only where necessary to correct spelling and to standardize printing format.

examined the patient, one of whom shall be the attending physician.

(6) Terminally ill or injured patient. A patient whose death is imminent or whose condition is hopeless unless he or she is artificially supported through the use of life-sustaining procedures.

§ 22-8A-4. Written declaration; requirements; form.

(a) Any adult person may execute a declaration directing the withholding or withdrawal of life-sustaining procedures in a terminal condition. The declaration made pursuant to this chapter shall be: (1) In writing; (2) signed by the person making the declaration, or by another person in the declarant's presence and by the declarant's expressed direction; (3) dated; and (4) signed in the presence of two or more witnesses at least 19 years of age neither of whom shall be the person who signed the declaration on behalf of and at the direction of the person making the declaration, related to the declarant by blood or marriage, entitled to any portion of the estate of the declarant according to the laws of intestate succession of this state or under any will of the declarant or codicil thereto, or directly financially responsible for declarant's medical care. The declaration of a qualified patient diagnosed as pregnant by the attending physician shall have no effect during the course of the qualified patient's pregnancy.

(b) It shall be the responsibility of declarant to provide for notification to his or her attending physician of the existence of the declaration. An attending physician who is so notified shall make the declaration, or a copy of the declaration, a part of the declarant's medical records.

(c) The declaration shall be substantially in the following form, but in addition may include other specific directions. Should any of the other specific directions be held to be invalid, such invalidity shall not affect other directions of the declaration which can be given effect without the invalid direction, and to this end the directions in the declaration are severable.

DECLARATION

Declaration made this _____ day of _____ (Month, year). I, _____, being of sound mind, willfully and voluntarily make known my desires that my dying shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining

procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care.

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this declaration shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

Signed _____

City, County and State of Residence

_____

_____

Date _____

The declarant has been personally known to me and I believe him or her to be of sound mind. I did not sign the declarant's signature above for or at the direction of the declarant. I am not related to the declarant by blood or marriage, entitled to any portion of the estate of the declarant according to the laws of intestate succession or under any will of declarant or codicil thereto, or directly financially responsible for declarant's medical care.

Witness _____

Witness _____

Date _____

§ 22-8A-5. Revocation of written declaration.

(a) A declaration may be revoked at any time by the declarant by any of the following methods:

(1) By being obliterated, burnt, torn, or otherwise destroyed or defaced in a manner indicating intention to cancel;

(2) By a written revocation of the declaration signed and dated by the declarant or person acting at the direction of the declarant; or

(3) By a verbal expression of the intent to revoke the declaration, in the presence of a witness 19 years of age or older who signs and dates a writing confirming that such expression of intent was made. Any verbal revocation shall become effective upon receipt by the attending physician of the above mentioned writing. The attending physician shall record in the patient's medical record the time, date and place of when he or she received notification of the revocation.

(b) There shall be no criminal or civil liability on the part of any person for failure to act upon a revocation made pursuant to this section unless that person has actual knowledge of the revocation.

§ 22-8A-6. Certification and confirmation of terminal condition.

An attending physician who has been notified of the existence of a declaration executed under this chapter, without delay after the diagnosis of a terminal condition of the declarant, shall take the necessary steps to provide for written certification and confirmation of the declarant's terminal condition, so that declarant may be deemed to be a qualified patient under this chapter.

§ 22-8A-7. Competency of declarant; liability of participating physician, facility, etc.

The desires of a qualified patient shall at all times supersede the effect of the declaration.

If the qualified patient is incompetent at the time of the decision to withhold or withdraw life-sustaining procedures, a declaration executed in accordance with section 22-8A-4 is presumed to be valid. For the purpose of this chapter, a physician or medical care facility may presume in the absence of actual notice to the contrary that an individual who executed a declaration was of sound mind when it was executed. The fact of an individual's having executed a declaration shall not be considered as an indication of a declarant's mental incompetency. Age of itself shall not be a bar to a determination of competency.

No physician, licensed health care professional, medical care facility or employee thereof who in good faith and pursuant to reasonable medical standards causes or participates in the withholding or withdrawing of life-sustaining procedures from a qualified patient pursuant to a declaration made in accordance with this chapter shall, as a result thereof, be subject to criminal or civil liability, or be found to have committed an act of unprofessional conduct.

§ 22-8A-8. Refusal of attending physician to comply with declaration; penalties for willful concealment, etc. of declaration or revocation.

(a) An attending physician who refuses to comply with the declaration of a qualified patient pursuant to this chapter shall not be liable for his refusal, but shall permit the qualified patient to be transferred to another physician.

(b) Any person who willfully conceals, cancels, defaces, obliterates or damages the declaration of another without such declarant's consent or who falsifies or forges a revocation of the declaration of another shall be guilty of a Class A misdemeanor.

(c) Any person who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of the revocation of a declaration, with the intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarant, and thereby, because of such act, directly causes life-sustaining procedures to be withheld or withdrawn and death to be hastened, shall be guilty of a Class C felony.

§ 22-8A-9. Withholding or withdrawal of procedures not suicide; execution of declaration not to affect sale, etc. of life insurance nor be condition for receipt of health care services; provisions of chapter cumulative.

(a) The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of this chapter shall not, for any purpose, constitute a suicide and shall not constitute assisting suicide.

(b) The making of a declaration pursuant to section 22-8A-4 shall not affect in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) No physician, medical care facility, or other health care provider, and no health care service plan, health maintenance organization, insurer issuing disability insurance, self-insured employee welfare benefit plan, nonprofit medical service corporation or mutual nonprofit hospital or hospital service corporation shall require any person to execute a declaration as a condition for being insured for, or receiving, health care services.

(d) Nothing in this chapter shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this chapter are cumulative.

(e) This chapter shall create no presumption concerning the intention of an individual who has not executed a declaration to consent to the use or withholding of life-sustaining procedures in the event of a terminal condition.

§ 22-8A-10. Provisions of chapter not an approval of mercy killing, etc.

Nothing in this chapter shall be construed to condone, authorize or approve mercy killing or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying as provided in this chapter.

Ala. Code §§ 22-8A-1 through 22-8A-10 (May 27, 1981) (Acts 1981, No. 81-772, §§ 1-10).

Arkansas

§ 82-3801. Right to die with dignity or to have life prolonged.

Every person shall have the right to die with dignity and to refuse and deny the use or application by any person of artificial, extraordinary, extreme or radical medical and surgical means or procedures calculated to prolong his life. Alternatively, every person shall have the right to request that such extraordinary means be utilized to prolong life to the extent possible.

§ 82-3802. Written request.

Any person, with the same formalities as are required by the laws of this State for the execution of a will, may execute a document exercising such right and refusing and denying the use or application by any person of artificial, extraordinary, extreme or radical medical or surgical means or procedures calculated to prolong his life. In the alternative, any person may request in writing that all means be utilized to prolong life.

§ 82-3803. Who may execute written request for another.

If any person is a minor or an adult who is physically or mentally unable to execute or is otherwise incapacitated from executing either document, it may be executed in the same form on his behalf:

(a) By either parent of the minor;

(b) By his spouse;

(c) If his spouse is unwilling or unable to act, by his child aged eighteen [18] or over;

(d) If he has more than one [1] child aged eighteen [18] or over, by a majority of such children;

(e) If he has no spouse or child aged eighteen [18] or over, by either of his parents;

(f) If he has no parent living, by his nearest living relative; or

(g) If he is mentally incompetent, by his legally appointed guardian.

Provided, that a form executed in compliance with this Section must contain a signed statement by two [2] physicians that extraordinary means would have to be utilized to prolong life.

§ 82-3804. No liability for actions in accordance with request.

Any person, hospital or other medical institution which acts or refrains from acting in reliance on and in compliance

with such document shall be immune from liability otherwise arising out of such failure to use or apply artificial, extraordinary, extreme or radical medical or surgical means or procedures calculated to prolong such person's life.

Ark. Stat. Ann. §§ 82-3801 through 82-3804 (March 30, 1977) (Acts 1977, No. 879, §§ 1-4).

California

§ 7185. Citation.

This act shall be known and may be cited as the Natural Death Act.

§ 7186. Legislative findings and declarations

The Legislature finds that adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of a terminal condition.

The Legislature further finds that modern medical technology has made possible the artificial prolongation of human life beyond natural limits.

The Legislature further finds that, in the interest of protecting individual autonomy, such prolongation of life for persons with a terminal condition may cause loss of patient dignity and unnecessary pain and suffering, while providing nothing medically necessary or beneficial to the patient.

The Legislature further finds that there exists considerable uncertainty in the medical and legal professions as to the legality of terminating the use or application of life-sustaining procedures where the patient has voluntarily and in sound mind evidenced a desire that such procedures be withheld or withdrawn.

In recognition of the dignity and privacy which patients have a right to expect, the Legislature hereby declares that the laws of the State of California shall recognize the right of an adult person to make a written directive instructing his physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition.

§ 7187. Definitions.

The following definitions shall govern the construction of this chapter.

(a) "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(b) "Directive" means a written document voluntarily executed by the declarant in accordance with the requirements of Section 7188. The directive, or a copy of the directive, shall be made part of the patient's medical records.

(c) "Life-sustaining procedure" means any medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physician, death is imminent whether or not such procedures are utilized. "Life-sustaining procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain.

(d) "Physician" means a physician and surgeon licensed by the Board of Medical Quality Assurance or the Board of Osteopathic Examiners.

(e) "Qualified patient" means a patient diagnosed and certified in writing to be afflicted with a terminal condition by two physicians, one of whom shall be the attending physician, who have personally examined the patient.

(f) "Terminal condition" means an incurable condition caused by injury, disease, or illness, which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the patient.

§ 7188. Directive to physicians.

Any adult person may execute a directive directing the withholding or withdrawal of life-sustaining procedures in a terminal condition. The directive shall be signed by the declarant in the presence of two witnesses not related to the declarant by blood or marriage and who would not be entitled to any portion of the estate of the declarant upon his decease under any will of the declarant or codicil thereto then existing or, at the time of the directive, by operation of law then existing. In addition, a witness to a directive shall not be the attending physician, an employee of the attending physician or a health facility in which the declarant is a patient, or any person who has a claim against any portion of the estate of the declarant upon his decease at the time of the execution of the directive. The directive shall be in the following form:

DIRECTIVE TO PHYSICIANS

Directive made this _____ day of _____ (month, year).
I _____, being of sound mind, willfully, and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

1. If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.

2. In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

3. If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.

4. I have been diagnosed and notified at least 14 days ago as having a terminal condition by _____, M.D., whose address is _____, and whose telephone number is _____. I understand that if I have not filled in the physician's name and address, it shall be presumed that I did not have a terminal condition when I made out this directive.

5. This directive shall have no force or effect five years from the date filled in above.

6. I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

Signed _____

City, County and State of Residence _____

The declarant has been personally known to me and I believe him or her to be of sound mind.

Witness _____

Witness _____

§ 7188.5. Directive to physicians: Patient in skilled nursing facility.

A directive shall have no force or effect if the declarant is a patient in a skilled nursing facility as defined in subdivision (c) of Section 1250 at the time the directive is executed unless one of the two witnesses to the directive is a patient advocate or ombudsman as may be designated by the State Department of Aging for this purpose pursuant to any other applicable provision of law. The patient advocate or ombudsman shall have the same qualifications as a witness under Section 7188.

The intent of this section is to recognize that some patients in skilled nursing facilities may be so insulated from a voluntary decisionmaking role, by virtue of the custodial nature of their care, as to require special assurance that they are capable of willfully and voluntarily executing a directive.

§ 7189. Revocation of directive.

(a) A directive may be revoked at any time by the declarant, without regard to his mental state or competency, by any of the following methods:

(1) By being canceled, defaced, obliterated, or burnt, torn, or otherwise destroyed by the declarant or by some person in his presence and by his direction.

(2) By a written revocation of the declarant expressing his intent to revoke, signed and dated by the declarant. Such revocation shall become effective only upon communication to the attending physician by the declarant or by a person acting on behalf of the declarant. The attending physician shall record in the patient's medical record the time and date when he received notification of the written revocation.

(3) By a verbal expression by the declarant of his intent to revoke the directive. Such revocation shall become effective only upon communication to the attending physician by the declarant or by a person acting on behalf of the declarant. The attending physician shall record in the patient's medical record the time, date, and place of the revocation and the time, date, and place, if different, of when he received notification of the revocation.

(b) There shall be no criminal or civil liability on the part of any person for failure to act upon a revocation made pursuant to this section unless that person has actual knowledge of the revocation.

§ 7189.5. Term of directive.

A directive shall be effective for five years from the date of execution thereof unless sooner revoked in a manner prescribed in Section 7189. Nothing in this chapter shall be construed to prevent a declarant from reexecuting a directive at any time in accordance with the formalities of Section 7188, including reexecution subsequent to a diagnosis of a terminal condition. If the declarant has executed more than one directive, such time shall be determined from the date of execution of the last directive known to the attending physician. If the declarant becomes comatose or is rendered incapable of communicating with the attending physician, the directive shall remain in effect for the duration of the comatose condition or until such time as the declarant's condition renders him or her able to communicate with the attending physician.

§ 7190. Immunity from civil or criminal liability.

No physician or health facility which, acting in accordance with the requirements of this chapter, causes the withholding or withdrawal of life-sustaining procedures from a qualified patient, shall be subject to civil liability therefrom. No licensed health professional, acting under the direction of a physician,

who participates in the withholding or withdrawal of life-sustaining procedures in accordance with the provisions of this chapter shall be subject to any civil liability. No physician, or licensed health professional acting under the direction of a physician, who participates in the withholding or withdrawal of life-sustaining procedures in accordance with the provisions of this chapter shall be guilty of any criminal act or of unprofessional conduct.

§ 7191. Duties of physician.

(a) Prior to effecting a withholding or withdrawal of life-sustaining procedures from a qualified patient pursuant to the directive, the attending physician shall determine that the directive complies with Section 7188, and, if the patient is mentally competent, that the directive and all steps proposed by the attending physician to be undertaken are in accord with the desires of the qualified patient.

(b) If the declarant was a qualified patient at least 14 days prior to executing or reexecuting the directive, the directive shall be conclusively presumed, unless revoked, to be the directions of the patient regarding the withholding or withdrawal of life-sustaining procedures. No physician, and no licensed health professional acting under the direction of a physician, shall be criminally or civilly liable for failing to effectuate the directive of the qualified patient pursuant to this subdivision. A failure by a physician to effectuate the directive of a qualified patient pursuant to this division shall constitute unprofessional conduct if the physician refuses to make the necessary arrangements, or fails to take the necessary steps, to effect the transfer of the qualified patient to another physician who will effectuate the directive of the qualified patient.

(c) If the declarant becomes a qualified patient subsequent to executing the directive, and has not subsequently reexecuted the directive, the attending physician may give weight to the directive as evidence of the patient's directions regarding the withholding or withdrawal of life-sustaining procedures and may consider other factors, such as information from the affected family or the nature of the patient's illness, injury, or disease, in determining whether the totality of circumstances known to the attending physician justify effectuating the directive. No physician, and no licensed health professional acting under the direction of a physician, shall be criminally or civilly liable for failing to effectuate the directive of the qualified patient pursuant to this subdivision.

§ 7192. Suicide: Insurance.

(a) The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of this chapter shall not, for any purpose, constitute a suicide.

(b) The making of a directive pursuant to Section 7188 shall not restrict, inhibit, or impair in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) No physician, health facility, or other health provider, and no health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or nonprofit hospital service plan, shall require any person to execute a directive as a condition for being insured for, or receiving, health care services.

§ 7193. Rights as cumulative.

Nothing in this chapter shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this chapter are cumulative.

§ 7194. Criminal penalties.

Any person who willfully conceals, cancels, defaces, obliterates, or damages the directive of another without such declarant's consent shall be guility of a misdemeanor. Any person who, except where justified or excused by law, falsifies or forges the directive of another, or willfully conceals or withholds personal knowledge of a revocation as provided in Section 7189, with the intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarant, and thereby, because of any such act, directly causes life-sustaining procedures to be withheld or withdrawn and death to thereby be hastened, shall be subject to prosecution for unlawful homicide as provided in Chapter 1 (commencing with Section 187) of Title 8 of Part 1 of the Penal Code.

§ 7195. Construction of chapter.

Nothing in this chapter shall be construed to condone, authorize, or approve mercy killing, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying as provided in this chapter.

1976 Cal. Stat., Chapter 1439, Code § Health and Safety, §§ 7185 through 7195 (Sept. 30, 1976).

Delaware

§ 2501. Definitions.

(a) 'Artificial means' shall mean manufactured or technical contrivances which may be attached to or integrated into the human body, but which are not normally a part of the human body.

(b) 'Attending physician' shall mean the physician selected by the patient or someone on his behalf, or assigned by a health care facility to the patient, which physician has primary responsibility for the treatment and care of the patient.

(c) 'Declarant' shall mean the person on whose behalf a declaration, in accordance with this chapter, is made.

(d) 'Declaration' shall mean a written statement voluntarily executed by the declarant or his agent directing the withholding or withdrawal of certain medical treatment, even if such treatment is the sole means of sustaining life, during a future state of incompetency.

(e) 'Maintenance medical treatment' shall mean any medical or surgical procedure or intervention which utilizes mechanical or other artifical means to sustain, restore, or supplant a vital function; and which would serve only to artifically prolong the dying process and delay the moment of death where death is imminent, whether or not such procedures are utilized. The words 'maintenance medical treatment' shall not include the administration of medication, nor the performance of any medical procedure necessary to provide comfort care or to alleviate pain.

(f) 'Terminal condition' shall mean any disease, illness, injury or condition sustained by any human being from which there is no reasonable medical expectation of recovery and which, as a medical probability, will result in the death of such human being regardless of the use or discontinuance of medical treatment implemented for the purpose of sustaining life, or the life processes.

§ 2502. Right of self-determination.

(a) An individual, legally adult, who is competent and of sound mind, has the right to refuse medical or surgical treatment if such refusal is not contrary to existing public health laws. Such individual has the right to make a written, dated declaration instructing any physician, including without limitation the treating physican, to cease or refrain from medical or surgical treatment during a possible pre-stated future incompetency of such person. The declaration shall take effect whenever the circumstances described in the declaration take place, and the fact they have taken place is confirmed in writing by two physicians.

(b) An adult person by written declaration may appoint an agent who will act on behalf of such appointor if, due to a condition resulting from illness or injury and, in the judgment of the attending physician, the appointor becomes incapable of making a decision in the exercise of the right to accept or refuse medical treatment.

(c) An agent appointed in accordance with this section may accept or refuse medical treatment proposed for the appointor if, in the judgment of the attending physician, the appointor is incapable of making that decision. This authority shall include the right to refuse medical treatment which would extend the appointor's life. An agent authorized to make decisions under this chapter has a duty to act in good faith, and with due regard for the benefit and interests of the appointor.

§ 2503. Written declaration.

(a) Any adult person may execute a declaration directing the withholding or withdrawal of maintenance medical treatment, where the person is in a terminal condition and under such circumstances as may be set forth in the declaration. The declaration made pursuant to this chapter shall be:

(1) in writing;

(2) signed by the person making the declaration, or by another person in the declarant's presence at the declarant's expressed direction;

(3) dated; and

(4) signed in the presence of two or more adult witnesses, as set forth in subsection (b).

(b) The declaration shall be signed by the declarant in the presence of two subscribing witnesses, neither of whom:

(1) is related to the declarant by blood or marriage;

(2) is entitled to any portion of the estate of the declarant under any will of the declarant or codicil thereto then existing nor, at the time of the declaration, is so entitled by operation of law then existing;

(3) has, at the time of the execution of the declaration, a present or inchoate claim against any portion of the estate of the declarant;

(4) has a direct financial responsibility for the declarant's medical care; or

(5) is an employee of the hospital or other health care facility in which the declarant is a patient.

(c) Each witness to the declaration shall verify that he is not prohibited, under subsection (b) of this section, from being a witness under the provision of this chapter.

(d) The declaration of a patient diagnosed as pregnant by the attending physician shall be of no effect during the course of the patient's pregnancy. Where a declaration is lacking any

requirement under this subsection and such defect is later corrected by amendment or codicil, whether formally or informally prepared, such declaration shall be valid *ab initio*, notwithstanding the earlier defect.

§ 2504. Revocation.

(a) The desires of a declarant who is competent shall at all times supercede the effect of the declaration. A declarant may revoke his declaration at any time, without regard to his mental state or competency. Any of the following methods is sufficient for revocation:

(1) Destruction, cancellation, obliteration, or mutilation of the declaration with an intent to revoke it. If physical disability has rendered the declarant unable to destroy, cancel, obliterate, or mutilate the declaration, he may direct another individual to do so in his presence;

(2) An oral statement made in the presence of two persons, each eighteen years of age or older, which expresses an intent contrary to that expressed in the declaration;

(3) Either a new declaration, made in the same manner with the same formality as the former declaration, which expresses an intent contrary to that expressed in the prior declaration; or a written revocation signed and dated by the declarant.

(b) There shall be no criminal nor civil liability on the part of any person for failure to act in accordance with a revocation, unless such person has actual or constructive knowledge of the revocation.

(c) If the declarant becomes comatose or is rendered incapable of communicating, the declaration shall remain in effect for the termination of the comatose condition, or until such time as the declarant's condition renders him able to communicate.

§ 2505. Health care personnel; legal immunity.

Physicians or nurses who act in reliance on a document executed in accordance with this chapter, where such health care personnel have no actual notice of revocation or contrary indication, by withholding medical procedures from an individual who executed such document shall be presumed to be acting in good faith, and unless negligent shall be immune from civil or criminal liability.

For purposes of this chapter a physician or nurse may presume, in the absence of actual notice to the contrary, that an individual who executed a document under this chapter was of sound mind when it was executed.

§ 2506. Safeguard provisions.

(a) Anyone who has good reason to believe that the withdrawal or withholding of a maintenance medical treatment in a particular case:

(1) is contrary to the most recent expressed wishes of a declarant;

(2) is being proposed pursuant to a Declaration that has been falsified, forged, or coerced; or

(3) is being considered without the benefit of a revocation which has been unlawfully concealed, destroyed, altered or cancelled; may petition the Court of Chancery for appointment of a guardian for such declarant.

(b) Upon receipt of a declaration, the hospital or the attending physician shall acknowledge receipt of same, and shall include the declaration as part of the declarant's medical records.

(c) A declaration shall be effective for ten years from the date it was declared or executed, unless sooner revoked in a manner permitted under this chapter. Nothing in this chapter shall be construed to prevent any person from re-executing a Declaration at any time.

(d) The Division of Aging and the Public Guardian shall have oversight over any declaration executed by a resident of a sanatorium, rest home, nursing home, boarding home, or related institution as the same is defined in § 1101, Title 16 of the Delaware Code. Such declaration shall have no force nor effect if the declarant is a resident of a sanatorium, rest home, nursing home, boarding home or related institution at the time the declaration is executed unless one of the witnesses is a person designated as a patient advocate or ombudsman by either the Division of Aging or the Public Guardian. The patient advocate or ombudsman must have the qualifications required of other witnesses under this Chapter.

§ 2507. Assumptions and presumptions.

(a) Neither the execution of a declaration under this Chapter nor the fact that maintenance medical treatment is withheld from a patient in accordance therewith shall, for any purpose, constitute a suicide.

(b) The making of a declaration pursuant to this Chapter shall not restrict, inhibit, nor impair in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed or presumed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of maintenance medical treatment from an insured patient, notwithstanding any term of the policy to the contrary.

(c) No physician, health facility, or other health care provider, nor any health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or non-profit hospital service plan, shall require any person to execute a Declaration as a condition to being

insured, or for receiving health care services, nor shall the signing of a Declaration be a bar.

(d) This chapter shall create no presumption concerning the intentions of an individual, who has not executed a declaration, to consent to the use or withholding of life-sustaining procedures in the event of a terminal condition.

§ 2508. Penalties.

(a) Whoever threatens directly or indirectly, coerces, or intimidates any person to execute a declaration directing the withholding or withdrawal of maintenance medical treatment shall be guilty of a misdemeanor and upon conviction shall be fined not less than $500 nor more than $1,000; be imprisoned not less than 30 days nor more than 90 days; or both. The Superior Court shall have jurisdiction over such offenses.

(b) Whoever knowingly conceals, destroys, falsifies or forges a document with intent to create the false impression that another person has directed that maintenance medical treatment be utilized for the prolongation of his life is guilty of a Class C felony.

(c) The Superior Court shall have jurisdiction over all offenses under this Chapter.

§ 2509. Exemption from liability; defense.

(a) No physician or other individual, nor any health care facility which, acting in accordance with the requirement of this Chapter, causes the withholding or withdrawal of life-sustaining procedures from a patient, shall be subject to civil liability therefrom. No physician or other person acting under the direction of a physician who participates in the withholding or withdrawal of a life-sustaining procedure in accordance with the provisions of this Chapter shall be guilty of any criminal act or of unprofessional conduct, other determinations to the contrary notwithstanding.

(b) In any action for malpractice governed by Chapter 68 of Title 18, brought against any attending physician or any health care facility, arising out of the observance of the provisions of this Chapter, it shall be a defense to such action that the attending physician or health care facility acted in accordance with a written declaration meeting all of the procedural requirements of this Chapter.

Section 2. This Act shall be known and may be cited as the Delaware Death with Dignity Act.

Section 3. Nothing in this Act shall be construed to condone, authorize, or approve of mercy killing; be construed to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying; nor be construed to be a method of defining or determining a technical state of death.

Section 4. If any provision of this Act or the application thereof to any person or circumstance is held invalid, such invalidity shall not affect other provisions or applications of this Act which can be given effect without the invalid provision or application, and to that end the provisions of this Act are declared to be severable.

Del. Code Ann. tit. 16, §§ 2501 through 2509 (July 12, 1982).

District of Columbia

§ 6-2421. Definitions.

For the purposes of this subchapter, the term:

(1) "Attending physician' means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(2) "Declaration' means a witnessed document in writing, voluntarily executed by the declarant in accordance with the requirements of § 6-2422.

(3) "Life-sustaining procedure' means any medical procedure or intervention, which, when applied to a qualified patient, would serve only to artificially prolong the dying process and where, in the judgment of the attending physician and a second physician, death will occur whether or not such procedure or intervention is utilized. The term "life-sustaining procedure' shall not include the administration of medication or the performance of any medical procedure deemed necessary to provide comfort care or to alleviate pain.

(4) "Physician' means a person authorized to practice medicine in the District of Columbia.

(5) "Qualified patient' means a patient who has executed a declaration in accordance with this subchapter and who has been diagnosed and certified in writing to be afflicted with a terminal condition by 2 physicians who have personally examined the patient, one of whom shall be the attending physician.

(6) "Terminal condition' means an incurable condition caused by injury, disease, or illness, which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the patient.

§ 6-2422. Declaration—Execution; form.

(a) Any persons 18 years of age or older may execute a declaration directing the withholding or withdrawal of life-sustaining procedures from themselves should they be in a

terminal condition. The declaration made pursuant to this subchapter shall be:

(1) In writing;

(2) Signed by the person making the declaration or by another person in the declarant's presence at the declarant's express direction;

(3) Dated; and

(4) Signed in the presence of 2 or more witnesses at least 18 years of age. In addition, a witness shall not be:

(A) The person who signed the declaration on behalf of and at the direction of the declarant;

(B) Related to the declarant by blood or marriage;

(C) Entitled to any portion of the estate of the declarant according to the laws of intestate succession of the District of Columbia or under any will of the declarant or codicil thereto;

(D) Directly financially responsible for declarant's medical care; or

(E) The attending physician, an employee of the attending physician, or an employee of the health facility in which the declarant is a patient.

(b) It shall be the responsibility of the declarant to provide for notification to his or her attending physician of the existence of the declaration. An attending physician, when presented with the declaration, shall make the declaration or a copy of the declaration a part of the declarant's medical records.

(c) The declaration shall be substantially in the following form, but in addition may include other specific directions not inconsistent with other provisions of this subchapter. Should any of the other specific directions be held to be invalid, such invalidity shall not affect other directions of the declaration which can be given effect without the invalid direction, and to this end the directions in the declaration are severable.

Declaration

Declaration made this _____ day of _____ (month/year).

I, _____, being of sound mind, willfully and voluntarily make known my desires that my dying shall not be artificially prolonged under the circumstances set forth below, do declare:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by 2 physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying

process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this declaration shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

Signed _____

Address _____

I believe the declarant to be of sound mind. I did not sign the declarant's signature above for or at the direction of the declarant. I am at least 18 years of age and am not related to the declarant by blood or marriage, entitled to any portion of the estate of the declarant according to the laws of intestate succession of the District of Columbia or under any will of the declarant or codicil thereto, or directly financially responsible for declarant's medical care. I am not the declarant's attending physician, an employee of the attending physician, or an employee of the health facility in which the declarant is a patient.

Witness _____

Witness _____

§ 6-2423. Same—Restrictions.

A declaration shall have no effect if the declarant is a patient in an intermediate care or skilled care facility as defined in the Health Care Facilities Regulation, enacted June 14, 1974 (Reg. 74-15; 20 DCR 1423) at the time the declaration is executed unless 1 of the 2 witnesses to the directive is a patient advocate or ombudsman. The patient advocate or ombudsman shall have the same qualifications as a witness under § 6-2422.

§ 6-2424. Same—Revocation.

(a) A declaration may be revoked at any time only by the declarant or at the express direction of the declarant, without regard to the declarant's mental state by any of the following methods:

(1) By being obliterated, burnt, torn, or otherwise destroyed or defaced by the declarant or by some person in the declarant's presence and at his or her direction;

(2) By a written revocation of the declaration signed and dated by the declarant or person acting at the direction of the declarant. Such revocation shall become effective only upon communication of the revocation to the attending physi-

cian by the declarant or by a person acting on behalf of the declarant. The attending physician shall record in the patient's medical record the time and date when he or she receives notification of the written revocation; or

(3) By a verbal expression of the intent to revoke the declaration, in the presence of a witness 18 years or older who signs and dates a writing confirming that such expression of intent was made. Any verbal revocation shall become effective only upon communication of the revocation to the attending physician by the declarant or by a person acting on behalf of the declarant. The attending physician shall record, in the patient's medical record, the time, date, and place of when he or she receives notification of the revocation.

(b) There shall be no criminal or civil liability on the part of any person for failure to act upon a revocation made pursuant to this section unless that person has actual knowledge of the revocation.

§ 6-2425. Physician's duty to confirm terminal condition.

(a) An attending physician who has been notified of the existence of a declaration executed under this subchapter, without delay after the diagnosis of a terminal condition of the declarant, shall take the necessary steps to provide for written certification and confirmation of the declarant's terminal condition, so that the declarant may be deemed to be a qualified patient under this subchapter.

(b) Once written certification and confirmation of the declarant's terminal condition is made a person becomes a qualified patient under this subchapter only if the attending physician verbally or in writing informs the patient of his or her terminal condition and documents such communication in the patient's medical record. If the patient is diagnosed as unable to comprehend verbal or written communications, such patient shall become a qualified patient as defined in § 6-2421, immediately upon written certification and confirmation of his or her terminal condition by the attending physician.

(c) An attending physician who does not comply with this section shall be considered to have committed an act of unprofessional conduct under § 2-1326.

§ 6-2426. Competency and intent of declarant.

(a) The desires of a qualified patient shall at all times supersede the effect of the declaration.

(b) If the qualified patient is incompetent at the time of the decision to withhold or withdraw life-sustaining procedures, a declaration executed in accordance with § 6-2422 is presumed to be valid. For the purpose of this subchapter, a physician or health facility may presume in the absence of actual notice to the contrary that an individual who executed a declaration was of sound mind when it was executed. The fact of an

individual's having executed a declaration shall not be considered as an indication of a declarant's mental incompetency.

§ 6-2427. Extent of medical liability; transfer of patient; criminal offenses.

(a) No physician, licensed health care professional, health facility, or employee thereof who in good faith and pursuant to reasonable medical standards causes or participates in the withholding or withdrawing of life-sustaining procedures from a qualifed patient pursuant to a declaration made in accordance with this subchapter shall, as a result thereof, be subject to criminal or civil liability, or be found to have committed an act of unprofessional conduct.

(b) An attending physician who cannot comply with the declaration of a qualified patient pursuant to this subchapter shall, in conjunction with the next of kin of the patient or other responsible individual, effect the transfer of the qualified patient to another physician who will honor the declaration of the qualified patient. Transfer under these circumstances shall not constitute abandonment. Failure of an attending physician to effect the transfer of the qualified patient according to this section, in the event he or she cannot comply with the directive, shall constitute unprofessional conduct as defined in § 2-1326.

(c) Any person who willfully conceals, cancels, defaces, obliterates, or damages the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another shall commit an offense, and upon conviction shall be fined an amount not to exceed $5,000 or be imprisoned for a period not to exceed 3 years, or both.

(d) Any person who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of the revocation of a declaration, with the intent to cause a withholding or withdrawal of life-sustaining procedures, contrary to the wishes of the declarant, and thereby, because of such act, directly causes life-sustaining procedures to be withheld or withdrawn and death to be hastened, shall be subject to prosecution for unlawful homicide pursuant to § 22-2401.

§ 6-2428. Exclusion of suicide; effect of declaration upon issuance.

(a) The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of this subchapter shall not, for any purpose, constitute a suicide and shall not constitute the crime of assisting suicide.

(b) The making of a declaration pursuant to § 6-2422 shall not affect in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of

life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) No physician, health facility, or other health care provider, and no health care service plan, health maintenance organization, insurer issuing disability insurance, self-insured employee welfare benefit plan, nonprofit medical service corporation, or mutual nonprofit hospital service corporation shall require any person to execute a declaration as a condition for being insured for, or receiving, health care services.

§ 6-2429. Preservation of existing rights.

(a) Nothing in this subchapter shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this subchapter are cumulative.

(b) This subchapter shall create no presumption concerning the intention of an individual who has not executed a declaration to consent to the use or withholding of life-sustaining procedures in the event of a terminal condition.

§ 6-2430. Effect of subchapter.

Nothing in this subchapter shall be construed to condone, authorize, or approve mercy-killing or to permit any affirmative or deliberate act or omission to end a human life other than to permit the natural process of dying as provided in this subchapter.

D.C. Code Ann. 16, §§ 6-2401 through 6-2430 (February 25, 1982).

Idaho

§ 39-4501. Short title.

This act shall be known and may be cited as the "Natural Death Act."

§ 39-4502. Statement of policy.

The legislature finds that adult persons have the fundamental right to control the decisions relating to the rendering of their medical care, including the decision to have life sustaining procedures withheld or withdrawn in instances of a terminal condition.

The legislature further finds that modern medical technology has made possible the artificial prolongation of human life beyond natural limits.

The legislature further finds that patients suffering from terminal conditions are sometimes unable to express their desire to withhold or withdraw such artificial life prolongation procedures which provide nothing medically necessary or beneficial to the patient because of the progress of the disease process which renders the patient comatose or unable to communicate with the physician.

In recognition of the dignity and privacy which patients have a right to expect, the legislature hereby declares that the laws of this state shall recognize the right of an adult person to make a written directive instructing his physician to withhold or withdraw life sustaining procedures when such person is suffering from a terminal condition and unable to instruct his physician regarding such procedures because of the terminal condition.

§ 39-4503. Definitions.

The following definitions shall govern the construction of this chapter:

(1) "Attending physician" means the physician licensed by the state board of medicine, selected by, or assigned to, the patient who has primary responsibility [responsibility] for the treatment and care of the patient.

(2) "Terminal condition" means an incurable physical condition caused by disease or illness which reasonable medical judgment determines shortens the lifespan of the patient.

(3) "Qualified patient" means a person of sound mind at least eighteen (18) years of age diagnosed by the attending physician to be afflicted with a terminal condition.

(4) "Artificial life-sustaining procedure" means any medical procedure or intervention which utilizes mechanical means to sustain or supplant a vital function which when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physician, death is imminent whether or not such procedures are utilized. Artificial life-sustaining procedures shall not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain.

§ 39-4504. Directive for withholding procedures.

Any qualified patient may execute a directive directing the withholding or withdrawal of artificial life-sustaining procedures when such patient becomes unconscious or unable to communicate with his attending physician because of the progress of the terminal condition resulting in his inability to voluntarily determine whether such procedures should be utilized and if such procedures would serve only to prolong the moment of his death and where his attending physician determines that his death is imminent whether or not such

procedures are utilized. The directive shall be signed by the qualified patient in the presence of two (2) witnesses who shall verify in such directive that they are not related to the qualified patient by blood or marriage, that they would not be entitled to any portion of the estate of the qualified patient upon his demise under any will of the qualified patient or codicil thereto then existing, at the time of the directive, or by operation of law then existing. In addition, the witnesses shall verify that they are not the attending physician, an employee of the attending physician or a health facility in which the qualified patient is a patient or any person who has a claim against any portion of the estate of the qualified patient upon his demise at the time of the execution of the directive. The directive shall be in the following form:

DIRECTIVE TO PHYSICIAN

Directive made this _____ day of _____ (month/year).

I, _____, being of sound mind, willfully and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances below:

1. In the absence of my ability to give directions regarding the use of artificial life-sustaining procedures as a result of the disease process of my terminal condition, it is my intention that such artificial life-sustaining procedures should not be used when they would serve only to artificially prolong the moment of my death and where my attending physician determines that my death is imminent whether or not the artificial life-sustaining procedures are utilized.

2. I have been diagnosed and notified that I have a terminal condition known as _____ by _____, M.D., whose address is _____ and whose telephone number is _____.

3. This directive shall have no force or effect after five years from the date filled in above.

4. I understand the full impact of this directive and I am emotionally and mentally competent to make this directive.

_____
(Name)
(City, County and State)

_____
Witness

_____
Witness

STATE OF IDAHO
County of Ada

We, _____, _____, and _____, the qualified patient and the witnesses respectively, whose names are

signed to the attached and foregoing instrument, being first duly sworn, do hereby declare to the undersigned authority that the qualified patient signed and executed the directive and that he signed willingly and he executed it as his free and voluntary act for the purposes therein expressed; and that each of the witnesses, in the presence and hearing of the qualified patient signed the directive as witness and that to the best of his knowledge the qualified patient was at the time 18 or more years of age, of sound mind and under no constraint or undue influence. We the undersigned witnesses further declare that we are not related to the qualified patient by blood or marriage; that we are not entitled to any portion of the estate of the qualified patient upon his decease under any will or codicil thereto presently existing or by operation of law then existing; that we are not the attending physician, an employee of the attending physician or a health facility in which the qualified patient is a patient, and that we are not a person who has a claim against any portion of the estate of the qualified patient upon his decease at the present time.

_____
Qualified Patient

_____
Witness

_____
Witness

SUBSCRIBED, sworn to and acknowledged before me by _____, the qualified patient, and subscribed and sworn to before me by _____ and _____, witnesses, this _____ day of _____, 19_____.

_____
Notary Public for the State of Idaho
Residing at Boise, Idaho

(SEAL)

§ 39-4505. Revocation.

(1) A directive may be revoked at any time by the qualified patient, without regard to his mental state or competence, by any of the following methods:

(a) By being cancelled, defaced, obliterated or burned, torn or otherwise destroyed by the qualified patient or by some person in his presence and by his direction.

(b) By a written revocation of the qualified patient expressing his intent to revoke, signed by the qualified patient.

(c) By a verbal expression by the qualified patient of his intent to revoke the directive.

(2) There shall be no criminal or civil liability on the part of any person for failure to act upon a revocation of a directive

made pursuant to this section unless that person has actual knowledge of the revocation.

§ 39-4506. Expiration of directive.

A directive shall be effective for five (5) years from the date of execution unless sooner revoked in a manner described in section 39-4505, Idaho Code. Nothing in this chapter shall be construed to prevent a qualified patient from reexecuting a directive at any time. If the qualified patient becomes comatose or is rendered incapable of communicating with the attending physician, the directive shall remain in effect for the duration of the comatose condition or until such time as the qualified patient's condition renders him able to communicate with the attending physician.

§ 39-4507. Immunity.

No physician or health facility, which, acting in accordance with a directive meeting the requirements of this chapter, causes the withholding or withdrawal of artificial life-sustaining procedures from a qualified patient, shall be subject to civil liability or criminal liability therefrom.

§ 39-4508. General provisions.

(1) This chapter shall have no effect or be in any manner construed to apply to persons not executing a directive pursuant to this chapter nor shall it in any manner affect the rights of any such persons or of others acting for or on behalf of such persons to give or refuse to give consent or withhold consent for any medical care, neither shall this chapter be construed to affect chapter 43, title 39, Idaho Code, in any manner.

(2) The making of a directive pursuant to this chapter shall not restrict, inhibit or impair in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of artificial life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(3) No physician, health facility or other health provider and no health care service plan, insurer issuing disability insurance, self-insured employee, welfare benefit plan, or nonprofit hospital service plan, shall require any person to execute a directive as a condition for being insured for, or receiving, health care services.

Idaho Code §§ 39-4501 through 39-4508 (March 1977).

Kansas

§ 65-28,101. Withholding or withdrawal of life-sustaining procedures; legislative finding and declaration.

The legislature finds that adult persons have the fundamental right to control the decisions relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of a terminal condition.

In order that the rights of patients may be respected even after they are no longer able to participate actively in decisions about themselves, the legislature hereby declares that the laws of this state shall recognize the right of an adult person to make a written declaration instructing his or her physician to withhold or withdraw life-sustaining procedures in the event of a terminal condition.

§ 65-28,102. Same; definitions.

As used in this act:

(a) "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(b) "Declaration" means a witnessed document in writing, voluntarily executed by the declarant in accordance with the requirements of K.S.A. 65-28,103.

(c) "Life-sustaining procedure" means any medical procedure or intervention which, when applied to a qualified patient, would serve only to prolong the dying process and where, in the judgment of the attending physician, death will occur whether or not such procedure or intervention is utilized. "Life-sustaining procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to provide comfort care or to alleviate pain.

(d) "Physician" means a person licensed to practice medicine and surgery by the state board of healing arts.

(e) "Qualified patient" means a patient who has executed a declaration in accordnce with this act and who has been diagnosed and certified in writing to be afflicted with a terminal condition by two physicians who have personally examined the patient, one of whom shall be the attending physician.

§ 65-28,103. Same; declaration authorizing; effect during pregnancy of qualifed patient; duty to notify attending physician; form of declaration; severability of directions.

(a) Any adult person may execute a declaration directing the withholding or withdrawal of life-sustaining procedures in a terminal condition. The declaration made pursuant to this act shall be: (1) In writing; (2) signed by the person making the declaration, or by another person in the declarant's presence

and by the declarant's expressed direction; (3) dated; and (4) signed in the presence of two or more witnesses at least eighteen (18) years of age neither of whom shall be the person who signed the declaration on behalf of and at the direction of the person making the declaration, related to the declarant by blood or marriage, entitled to any portion of the estate of the declarant according to the laws of intestate succession of this state or under any will of the declarant or codicil thereto, or directly financially responsible for declarant's medical care. The declaration of a qualified patient diagnosed as pregnant by the attending physician shall have no effect during the course of the qualified patient's pregnancy.

(b) It shall be the responsibility of declarant to provide for notification to his or her attending physician of the existence of the declaration. An attending physician who is so notified shall make the declaration, or a copy of the declaration, a part of the declarant's medical records.

(c) The declaration shall be substantially in the following form, but in addition may include other specific directions. Should any of the other specific directions be held to be invalid, such invalidity shall not affect other directions of the declaration which can be given effect without the invalid direction, and to this end the directions in the declaration are severable.

DECLARATION

Declaration made this _____ day of _____ (month,year). I, _____, being of sound mind, willfully and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, do hereby declare:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artifically prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care.

In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this declaration shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

Signed _____

City, County and State of Residence _____

_____

The declarant has been personally known to me and I believe him or her to be of sound mind. I did not sign the declarant's signature above for or at the direction of the declarant. I am not related to the declarant by blood or marriage, entitled to any portion of the estate of the declarant according to the laws of intestate succession or under any will of declarant or codicil thereto, or directly financially responsible for declarant's medical care.

Witness _____

Witness _____

§ 65-28,104. Same; revocation of declaration.

(a) A declaration may be revoked at any time by the declarant by any of the following methods:

(1) By being obliterated, burnt, torn, or otherwise destroyed or defaced in a manner indicating intention to cancel;

(2) by a written revocation of the declaration signed and dated by the declarant or person acting at the direction of the declarant; or

(3) by a verbal expression of the intent to revoke the declaration, in the presence of a witness eighteen (18) years of age or older who signs and dates a writing confirming that such expression of intent was made. Any verbal revocation shall become effective upon receipt by the attending physician of the above mentioned writing. The attending physician shall record in the patient's medical record the time, date and place of when he or she received notification of the revocation.

(b) There shall be no criminal or civil liability on the part of any person for failure to act upon a revocation made pursuant to this section unless that person has actual knowledge of the revocation.

§ 65-28,105. Same; written certification and confirmation of declarant's terminal condition; effect of failure to comply.

An attending physician who has been notified of the existence of a declaration executed under this act, without delay after the diagnosis of a terminal condition of the declarant, shall take the necessary steps to provide for written certification and confirmation of the declarant's terminal condition, so that declarant may be deemed to be a qualified patient under this act.

An attending physician who fails to comply with this section shall be deemed to have refused to comply with the declaration and shall be subject to subsection (a) of K.S.A. 65-28,107.

§ 65-28,106. Same; desires of qualified patient supersede declaration; presumptions relating to declaration; immunity from civil or criminal liability for persons acting pursuant to declaration.

The desires of a qualified patient shall at all times supersede the effect of the declaration.

If the qualified patient is incompetent at the time of the decision to withhold or withdraw life-sustaining procedures, a declaration executed in accordance with K.S.A. 65-28,103 is presumed to be valid. For the purpose of this act, a physician or medical care facility may presume in the absence of actual notice to the contrary that an individual who executed a declaration was of sound mind when it was executed. The fact of an individual's having executed a declaration shall not be considered as an indication of a declarant's mental incompetency. Age of itself shall not be a bar to a determination of competency.

No physician, licensed health care professional, medical care facility or employee thereof who in good faith and pursuant to reasonable medical standards causes or participates in the withholding or withdrawing of life-sustaining procedures from a qualified patient pursuant to a declaration made in accordance with this act shall, as a result thereof, be subject to criminal or civil liability, or be found to have committed an act of unprofessional conduct.

§ 65-28,107. Same; attending physician's refusal to comply with declaration of qualified patient; transfer of patient; unprofessional conduct; unlawful act.

(a) An attending physician who refuses to comply with the declaration of a qualified patient pursuant to this act shall effect the transfer of the qualified patient to another physician. Failure of an attending physician to comply with the declaration of a qualified patient and to effect the transfer of the qualified patient shall constitute unprofessional conduct as defined in K.S.A. 65-2837.

(b) Any person who willfully conceals, cancels, defaces, obliterates or damages the declaration of another without such declarant's consent or who falsifies or forges a revocation of the declaration of another shall be guilty of a class A misdemeanor.

(c) Any person who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of the revocation of a declaration, with the intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarant, and thereby, because of

such act, directly causes life-sustaining procedures to be withheld or withdrawn and death to be hastened, shall be guilty of a class E felony.

§ 65-28,108. Same; construction and effect of act.

(a) The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of this act shall not, for any purpose, constitute a suicide and shall not constitute the crime of assisting suicide as defined by K.S.A. 21-3406.

(b) The making a declaration pursuant to K.S.A. 65-28,103 shall not affect in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) No physician, medical care facility, or other health care provider, and no health care service plan, health maintenance organization, insurer issuing disability insurance, self-insured employee welfare benefit plan, nonprofit medical service corporation or mutual nonprofit hospital service corporation shall require any person to execute a declaration as a condition for being insured for, or receiving, health care services.

(d) Nothing in this act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this act are cumulative.

(e) This act shall create no presumption concerning the intention of an individual who has not executed a declaration to consent to the use or withholding of life-sustaining procedures in the event of a terminal condition.

§ 65-28,109. Same; act not to be construed to condone or approve mercy killing or to permit other than natural process of dying.

Nothing in this act shall be construed to condone, authorize or approve mercy killing or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying as provided in this act.

Kan. Stat. Ann. §§ 65-28,101 through 65-28,109 (July 1, 1979).

Nevada

§ 449.540 Definitions.

As used in NRS 449.540 to 449.680, inclusive, unless the

context otherwise requires, the words and terms defined in NRS 449.550 to 449.590, inclusive, have the meanings ascribed to them in those sections.

§ 449.550 "Attending physician" defined.

"Attending physician" means the physician, selected by or assigned to a patient, who has primary responsibility for the treatment and care of the patient.

§ 449.560 "Declaration" defined.

"Declaration" means a written document executed by an adult person directing that when he is in a terminal condition and becomes comatose or is otherwise rendered incapable of communicating with his attending physician, life-sustaining procedures shall not be applied.

§ 449.570 "Life-sustaining procedure" defined.

"Life-sustaining procedure" means a medical procedure which utilizes mechanical or other artificial methods to sustain, restore or supplant a vital function. The term does not include medication or procedures necessary to alleviate pain.

§ 449.580 "Physician" defined.

"Physician" means any person licensed to practice medicine or osteopathy.

§ 449.590 "Terminal condition" defined.

"Terminal condition" means an incurable condition which is such that the application of life-sustaining procedures serves only to postpone the moment of death.

§ 449.600 Execution of declaration.

Any adult person may execute a declaration directing that when he is in a terminal condition and becomes comatose or is otherwise rendered incapable of communicating with his attending physician, life-sustaining procedures be withheld or withdrawn from him. The person shall execute the declaration in the same manner in which a will is executed, except that a witness may not be:

1. Related to the declarant by blood or marriage.

2. The attending physician.

3. An employee of the attending physician or of the hospital or other health and care facility in which the declarant is a patient.

4. A person who has a claim against any portion of the estate of the declarant.

§ 449.610 Form of declaration; entry and removal of declaration from medical records.

The declaration shall be in substantially the following form:

DIRECTIVE TO PHYSICIANS

Date _____

I, _____, being of sound mind, intentionally and voluntarily declare:

1. If at any time I am in a terminal condition and become comatose or am otherwise rendered incapable of communicating with my attending physician, and my death is imminent because of an incurable disease, illness or injury, I direct that life-sustaining procedures be withheld or withdrawn, and that I be permitted to die naturally.

2. It is my intention that this directive be honored by my family and attending physician as the final expression of my legal right to refuse medical or surgical treatment and to accept the consequences of my refusal.

3. If I have been found to be pregnant, and that fact is known to my physician, this directive is void during the course of my pregnancy. I understand the full import of this directive, and I am emotionally and mentally competent to execute it.

Signed _____

City, County and State of Residence

_____

The declarant has been personally known to me and I believe _____ to be of sound mind.

Witness _____

Witness _____

Section 3 of the declaration form should be omitted for male declarants.

The executed declaration, or a copy thereof signed by the declarant and the witnesses, shall be placed in the medical record of the declarant and a notation made of its presence and the date of its execution. A notation of the circumstances and date of removal of a declaration shall be entered in the medical record if the declaration is removed for any reason.

§ 449.620 Revocation of declaration; immunity in case of failure to act upon revocation.

(1) A declaration may be revoked at any time by the declarant in the same way in which a will may be revoked, or by a verbal expression of intent to revoke. A verbal revocation is effective upon communication to the attending physician by the declarant or another person communicating it on behalf of the declarant. The attending physician shall record the verbal revocation and the date on which he received it in the medical record of the declarant.

(2) No person is liable in a civil or criminal action for failure to act upon a revocation of a declaration unless the person had actual knowledge of the revocation.

§ 449.630 Immunity for withholding or withdrawing life-sustaining procedures.

No hospital or other health and care facility, physician or person working under the direction of a physician who causes the withholding or withdrawal of life-sustaining procedures from a patient in a terminal condition who has a declaration in effect and has become comatose or has otherwise been rendered incapable of communicating with his attending physician is subject to criminal or civil liability or to a charge of unprofessional conduct or malpractice as a result of an action taken in accordance with NRS 449.600 to 449.660, inclusive.

§ 449.640 Immunity in case of failure to follow directions of patient.

(1) If a patient in a terminal condition has a declaration in effect and becomes comatose or is otherwise rendered incapable of communicating with his attending physician, the physician shall give weight to the declaration as evidence of the patient's directions regarding the application of life-sustaining procedures, but the attending physician may also consider other factors in determining whether the circumstances warrant following the directions.

(2) No hospital or other health care facility, physician or person working under the direction of a physician is subject to criminal or civil liability for failure to follow the directions of the patient to withhold or withdraw life-sustaining procedures.

§ 449.650 Effect of declaration respecting suicide, insurance policies; execution of declaration may not be required as condition for insurance, health care services.

(1) A person does not commit suicide by executing a declaration.

(2) The execution of a declaration does not restrict, inhibit or impair the sale, procurement or issuance of any policy of insurance, nor shall it be deemed to modify any term of an existing policy of insurance. No policy of life insurance is impaired or invalidated in whole or in part by the withholding or withdrawal of life-sustaining procedures from an insured person, regardless of any term of the policy.

(3) No person may require another to execute a declaration as a condition for being insured for or receiving health care services.

§ 449.660 Penalties.

(1) Any person who willfully conceals, cancels, defaces, obliterates or damages the declaration of another without the consent of the declarant is guilty of a misdemeanor.

(2) Any person who falsifes or forges a document purporting to be the declaration of another, or who willfully conceals or withholds personal knowledge of a revocation, with the

intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarant and thereby directly causes life-sustaining procedures to be withheld or withdrawn and death to be hastened is guilty of murder.

§ 449.670 Termination of life.

Nothing in NRS 449.600 to 449.620, inclusive, permits any affirmative or deliberate act or omission which ends life other than to permit the natural process of dying.

§ 449.680 Other right or responsibility to withhold or withdraw life-sustaining procedures not limited.

Nothing in NRS 449.610 to 449.660, inclusive, limits the right or responsibility which a person may otherwise have to withhold or withdraw life-sustaining procedures.

§ 449.690 Effect of instrument executed before July 1, 1977.

An instrument executed before July 1, 1977, which clearly expresses the intent of the declarant to direct the withholding or withdrawal of life-sustaining procedures from him when he is in a terminal condition and becomes comatose or is otherwise rendered incapable of communicating with his attending physician shall, if executed in a manner which attests voluntary execution and not subsequently revoked, be given the same effect as a declaration prepared and executed in accordance with NRS 449.540 to 449.680, inclusive.

Nev. Rev. Stat. §§ 449.550 through 449.590 (May 6, 1977).

New Mexico

§ 24-7-1. Short title.

This act [24-7-1 to 24-7-11 NMSA 1978] may be cited as the "Right to Die Act."

§ 24-7-2. Definitions.

As used in the Right to Die Act:

(A) "maintenance medical treatment" means medical treatment designed solely to sustain the life processes;

(B) "minor" means a person who has not reached the age of majority;

(C) "physician" means an individual licensed to practice medicine in New Mexico; and

(D) "terminal illness" means an illness that will result in death as defined in Section 12-2-4 NMSA 1978, regardless of the use or discontinuance of maintenance medical treatment.

§ 24-7-3. Execution of a document.

(A) An individual of sound mind and having reached the age of majority may execute a document directing that if he is ever certified under the Right to Die Act as suffering from a

terminal illness then maintenance medical treatment shall not be utilized for the prolongation of his life.

(B) A document described in Subsection A of this section is not valid unless it has been executed with the same formalities as required of a valid will pursuant to the provisions of the Probate Code [45-1-101 to 45-7-401 NMSA 1978].

§ 24-7-4. Execution of a document for the benefit of a terminally ill minor.

(A) If a minor has been certified under the Right to Die Act as suffering a terminal illness, the following individual may execute the document on his behalf:

(1) the spouse, if he has reached the age of majority; or

(2) if there is no spouse, or if the spouse is not available at the time of the certification or is otherwise unable to act, then either the parent or guardian of the minor.

(B) An individual named in Subsection A of this section may not execute a document:

(1) if he has actual notice of contrary indications by the minor who is terminally ill; or

(2) when executing as a parent or guardian, if he has actual notice of opposition by either another parent or guardian or a spouse who has attained the age of majority.

(C) A document described in Subsection A of this section is not valid unless it has been executed with the same formalities as required of a valid will under the Probate Code, and has been certified upon its face by a district court judge pursuant to Subsection D of this section.

(D) Any person executing a document pursuant to the provisions of this section shall petition the district court for the county in which the minor is domiciled, or the county in which the minor is being maintained, for certification upon the face of the document. The court shall appoint a guardian ad litem to represent the minor and may hold an evidentiary hearing before certification. All costs shall be charged to the petitioner. If the district court judge is satisfied that all requirements of the Right to Die Act have been satisfied, that the document was executed in good faith and that the certification of the terminal illness was in good faith, then he shall certify the document.

§ 24-7-5. Certification of a terminal illness.

(A) For purposes of the Right to Die Act, certification of a terminal illness may be rendered only in writing by two physicians, one of whom is the physician in charge of the individual who is terminally ill. A copy of any such certification shall be kept in the records of the medical facility where the patient is being maintained. If the patient is not being maintained in a medical facility, a copy shall be retained by the physician in charge in his own case records.

(B) A physician who certifies a terminal illness under this section is presumed to be acting in good faith. Unless it is alleged and proved that his action violated the standard of reasonable professional care and judgment under the circumstances, he is immune from civil or criminal liability that otherwise might be incurred.

§ 24-7-6. Revocation of a document.

(A) An individual who has executed a document under the Right to Die Act may, at any time thereafter, revoke the document. Revocation may be accomplished by destroying the document, or by contrary indication expressed in the presence of one witness who has reached the age of majority.

(B) A minor may revoke the document in the manner provided under Subsection A of this section. During the remainder of his terminal illness, any such revocation may constitute actual notice of his contrary indication.

§ 24-7-7. Physician's immunity from liability.

(A) After certification of a terminal illness under the Right to Die Act, a physician who relies on a document executed under that act, of which he has no actual notice of revocation or contrary indication, and who withholds maintenance medical treatment from the terminally ill individual who executed the document, is presumed to be acting in good faith. Unless it is alleged and proved that the physician's actions violated the standard of reasonable professional care and judgment under the circumstances, he is immune from civil or criminal liability that otherwise might be incurred.

(B) A physician who relies on a document executed on behalf of a terminally ill minor under the Right to Die Act and certified on its face by a district court judge pursuant to Section 4 of that act, and who withholds maintenance medical treatment from the terminally ill minor on whose behalf the document was executed, is presumed to be acting in good faith, if he has no actual notice of revocation or contrary indication. Unless it is alleged and proved that the physician's actions violated the standard of reasonable professional care and judgment under the circumstances, he is immune from civil or criminal liability that otherwise might be incurred.

(C) In the absence of actual notice to the contrary, a physician may presume that an individual who executed a document under the Right to Die Act was of sound mind when the document was executed.

(D) Any hospital or medical institution or its employees which act or refrain from acting in reasonable reliance on and in compliance with a document executed under the Right to Die Act shall be immune from civil or criminal liability that otherwise might be incurred.

§ 24-7-8. Insurance.

(A) The withholding of maintenance medical treatment from any individual pursuant to the provisions of the Right to Die Act shall not, for any purpose, constitute a suicide.

(B) The execution of a document pursuant to the Right to Die Act shall not restrict, inhibit or impair in any manner the sale, procurement or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding of maintenance medical treatment under the Right to Die Act from an insured individual, notwithstanding any term of the policy to the contrary.

(C) No physician, health facility or other health care provider, and no health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan or nonprofit hospital service plan shall require any person to execute a document pursuant to the Right to Die Act as a condition for being insured for, or receiving, health care service.

§ 24-7-9. Cumulative provisions.

Nothing in the Right to Die Act shall impair or supersede any existing legal right or legal responsibility which any person may have to effect the withholding or nonutilization of any maintenance medical treatment in any lawful manner. In such respect the provisions of the Right to Die Act are cumulative.

§ 24-7-10. Penalties.

(A) Whoever knowingly and willfully conceals, destroys, falsifies or forges a document with intent to create the false impression that another person has directed that no maintenance medical treatment be utilized for the prolongation of his life or the life of a minor, or whoever knowingly and willfully conceals evidence of revocation of a document executed pursuant to the Right to Die Act, is guilty of a second degree felony, punishable by imprisonment in the penitentiary for a period of not less than ten years nor more than fifty years or a fine of not more than ten thousand dollars ($10,000) or both.

(B) Whoever knowingly and willfully conceals, destroys, falsifies or forges a document with intent to create the false impression that another person has not directed that maintenance medical treatment not be utilized for the prolongation of his life is guilty of a third degree felony, punishable by imprisonment in the penitentiary for a term of not less than two years nor more than ten years or a fine of not more than five thousand dollars ($5,000) or both.

(C) Whoever executes a document under the Right to Die Act for the benefit of a terminally ill minor and who either has actual notice of contrary indications by the minor who is terminally ill, or, when executing as a parent or guardian, has actual notice of opposition by either another parent or guard-

ian or a spouse, is guilty of a second degree felony, punishable by imprisonment in the penitentiary for a period of not less than ten years nor more than fifty years, or by a fine of not more than ten thousand dollars ($10,000) or both.

§ 24-7-11. Application.

The Right to Die Act applies to all persons executing documents in conformity with that act on or after the effective date of the Right to Die Act.

N.M. Stat. Ann. §§ 24-7-1 through 24-7-10 (April 7, 1977).

North Carolina

§ 90-320. General purpose of article.

(a) The General Assembly hereby recognizes that an individual's rights as a citizen of this State include the right to a peaceful and natural death. This Article is to establish a procedure for the exercise of that right and to state expressly the extent of a physician's obligation to preserve the life of his patient in situations where artificial means may be used to sustain the circulatory and respiratory functions for an indefinite period.

(b) Nothing in this Article shall be construed to authorize any affirmative or deliberate act or omission to end life other than to permit the natural process of dying. Nothing in this Article shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this Article are cumulative.

§ 90-321. Right to a natural death.

(a) As used in this Article the term:

(1) "Declarant" means a person who has signed a declaration in accordance with subsection (c);

(2) "Extraordinary means" is defined as any medical procedure or intervention which in the judgment of the attending physician would serve only to postpone artificially the moment of death by sustaining, restoring, or supplanting a vital function;

(3) "Physician" means any person licensed to practice medicine under Article 1 of Chapter 90 of the laws of the State of North Carolina.

(b) If a person has declared, in accordance with subsection (c) below, a desire that his life not be prolonged by extraordinary means; and the declaration has not been revoked in accordance with subsection (e); and (1) It is deter-

mined by the attending physician that the declarant's present condition is

a. Terminal; and

b. Incurable; and

(2) There is confirmation of the declarant's present condition as set out above in subdivision (b)(1) by a physician other than the attending physician; then extraordinary means may be withheld or discontinued upon the direction and under the supervision of the attending physician.

(c) The attending physician may rely upon a signed, witnessed, dated and proved declaration:

(1) Which expresses a desire of the declarant that no extraordinary means be used to prolong his life if his condition is determined to be terminal and incurable; and

(2) Which states that the declarant is aware that the declaration authorizes a physician to withhold or discontinue the extraordinary means; and

(3) Which has been signed by the declarant in the presence of two witnesses who believe the declarant to be of sound mind and who state that they (i) are not related within the third degree to the declarant or to the declarant's spouse, (ii) do not know or have a reasonable expectation that they would be entitled to any portion of the estate of the declarant upon his death under any will of the declarant or codicil thereto then existing or under the Intestate Succession Act as it then provides, (iii) are not the attending physician, or an employee of the attending physician, or an employee of a health facility in which the declarant is a patient, or an employee of a nursing home or any group-care home in which the declarant resides, and (iv) do not have a claim against any portion of the estate of the declarant at the time of the declaration; and

(4) Which has been proved before a clerk or assistant clerk of superior court, or a notary public who certifies substantially as set out in subsection (d) below.

(d) The following form is specifically determined to meet the requirements above:

"Declaration of A Desire For A Natural Death

"I, _____, being of sound mind, desire that my life not be prolonged by extraordinary means if my condition is determined to be terminal and incurable. I am aware and understand that this writing authorizes a physician to withhold or discontinue extraordinary means.

"This the _____ day of _____, _____

Signature _____

"I hereby state that the declarant, _____, being of sound mind signed the above declaration in my presence and that I am not related to the declarant by blood or marriage and that I do not know or have a reasonable expectation that I would be entitled to any portion of the estate of the declarant, under any existing will or codicil of the declarant, or as an heir under the Intestate Succession Act if the declarant died on this date without a will. I also state that I am not the declarant's attending physician or an employee of the declarant's attending physician, or an employee of a health facility in which the declarant is a patient or an employee of a nursing home or any group-care home where the declarant resides. I further state that I do not now have any claim against the declarant.

Witness _____

Witness _____"

The clerk or the assistant clerk, or a notary public may, upon proper proof, certify the declaration as follows:

"Certificate

"I, _____, Clerk (Assistant Clerk) of Superior Court or Notary Public (circle one as appropriate) for _____ County hereby certify that _____, the declarant, appeared before me and swore to me and to the witnesses in my presence that this instrument is his Declaration Of A Desire For A Natural Death, and that he had willingly and voluntarily made and executed it as his free act and deed for the purposes expressed in it.

"I further certify that _____ and _____, witnesses, appeared before me and swore that they witnessed _____, declarant, sign the attached declaration, believing him to be of sound mind; and also swore that at the time they witnessed the declaration (i) they were not related within the third degree to the declarant or to the declarant's spouse, and (ii) they did not know or have a reasonable expectation that they would be entitled to any portion of the estate of the declarant upon the declarant's death under any will of the declarant or codicil thereto then existing or under the Intestate Succession Act as it provides at that time, and (iii) they were not a physician attending the declarant or an employee of an attending physician or an employee of a health facility in which the declarant was a patient or an employeee of a nursing home or any group-care home in which the declarant resided, and (iv) they did not have a claim against the declarant. I further certify that I am satisfied as to the genuineness and due execution of the declaration. This the _____ of _____, _____.

_____
Clerk (Assistant Clerk) of Superior Court
or Notary Public (circle one as appropriate)
for the County of _____"

The above declaration may be proved by the clerk or the assistant clerk, or a notary public in the following manner:

(1) Upon the testimony of the two witnesses; or

(2) If the testimony of only one witness is available, then

a. Upon the testimony of such witness, and

b. Upon proof of the handwriting of the witness who is dead or whose testimony is otherwise unavailable, and

c. Upon proof of the handwriting of the declarant, unless he signed by his mark; or upon proof of such other circumstances as will satisfy the clerk or assistant clerk of the superior court, or a notary public as to the genuineness and due execution of the declaration.

(3) If the testimony of none of the witnesses is available, such declaraton may be proved by the clerk or assistant clerk, or a notary public

a. Upon proof of the handwriting of the two witnesses who testimony is unavailable, and

b. Upon compliance with paragraph c of subdivision (2) above.

Due execution may be established, where the evidence required above is unavoidably lacking or inadequate, by testimony of other competent witnesses as to the requisite facts.

The testimony of a witness is unavailable within the meaning of this subsection when the witness is dead, out of the State, not to be found within the State, insane or otherwise incompetent, physically unable to testify or refuses to testify.

If the testimony of one or both of the witnesses is not available the clerk or the assistant clerk, or a notary public of superior court may, upon proper proof, certify the declaration as follows:

"Certificate

"I _____, Clerk (Assistant Clerk) of Court for the Superior Court or Notary Public (circle one as appropriate) of _____ County hereby certify that based upon the evidence before me I am satisfied as to the genuineness and due execution of the attached declaration by _____, declarant, and that the declarant's signature was witnessed by

_____, and _____, who at the time of the declaration met the qualifications of G.S. 90-321(c)(3).

"This the _____ day of _____.

_____

Clerk (Assistant Clerk) of Superior Court
or Notary Public (circle one as appropriate)
for _____ County."

(e) The above declaration may be revoked by the declarant, in any manner by which he is able to communicate his intent to revoke, without regard to his mental or physical condition. Such revocation shall become effective only upon communication to the attending physician by the declarant or by an individual acting on behalf of the declarant.

(f) The execution and consummation of declarations made in accordance with subsection (c) shall not constitute suicide for any purpose.

(g) No person shall be required to sign a declaration in accordance with subsection (c) as a condition for becoming insured under any insurance contractor for receiving any medical treatment.

(h) The withholding or discontinuance of extraordinary means in accordance with this section shall not be considered the cause of death for any civil or criminal purposes nor shall it be considered unprofessional conduct. Any person, institution or facility against whom criminal or civil liability is asserted because of conduct in compliance with this section may interpose this section as a defense.

(i) Any certificate in the form provided by this section prior to July 1, 1979 shall continue to be valid.

§ 90-322. Procedures for natural death in the absence of a declaration.

(a) If a person is comatose and there is no reasonable possibility that he will return to a cognitive sapient state or is mentally incapacitated, and:

(1) It is determined by the attending physician that the person's present condition is:

a. Terminal; and

b. Incurable; and

c. Irreversible; and

(2) There is confirmation of the person's present condition as set out above in this subsection, by a majority of a committee of three physicians other than the attending physician; and

(3) A vital function of the person could be restored by extraordinary means or a vital function of the person is being sustained by extraordinary means;

then, extraordinary means may be withheld or discontinued in accordance with subsection (b).

(b) If a person's condition has been determined to meet the conditions set forth in subsection (a) and no instrument has been executed as provided in G.S. 90-321 the extraordinary means to prolong life may be withheld or discontinued upon the direction and under the supervision of the attending physician at the request (i) of the person's spouse, or (ii) of a guardian of the person, or (iii) of a majority of the relatives of the first degree, in that order. If none of the above are available then at the discretion of the attending physician the extraordinary means may be discontinued upon the direction and under the supervision of the attending physician.

(c) Repealed by Session Laws 1979, c. 715, s. 2.

(d) The withholding or discontinuance of such extraordinary means shall not be considered the cause of death for any civil or criminal purpose nor shall it be considered unprofessional conduct. Any person, institution or facility against whom criminal or civil liability is asserted because of conduct in compliance with this section may interpose this section as a defense.

N.C. Gen. Stat. §§ 90-320 through 90-322 (July 1, 1977).

Oregon

§ 97.050 Definitions for ORS 97.050 to 97.090.

As used in ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990:

(1) "Attending physician" means the physician with primary responsibility for the care and treatment of a patient.

(2) "Directive" means a written document voluntarily executed by a declarant in accordance with the requirements set forth in ORS 97.055.

(3) "Life-sustaining procedure" means any medical procedure or intervention that utilizes mechanical or other artificial means to sustain, restore or supplant a vital function of a qualified patient that is used to maintain the life of a person suffering from a terminal condition and serves only to artificially prolong the moment of death and when death is imminent whether or not such procedures are used. 'Life-sustaining procedure' does not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain.

(4) "Physician" means an individual licensed to practice medicine by the Board of Medical Examiners for the State of Oregon.

(5) "Qualified patient" means an individual, 18 years of age or older, whom the attending physician and one other physician, upon diagnostic examination of the patient, certify to be suffering from a terminal condition.

(6) "Terminal condition" means an incurable condition caused by injury, disease or illness which, regardless of the application of life-sustaining procedures would within reasonable medical judgment produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the patient.

§ 97.055 Execution of directive; form; witness qualifications and responsibility; revocation of directive.

(1) An individual of sound mind and 18 years of age or older may at any time execute or reexecute a directive directing the withholding or withdrawal of life-sustaining procedures should the declarant become a qualified patient. The directive shall be in the following form:

DIRECTIVE TO PHYSICIANS

Directive made this _____ day of _____ (month,year). I _____, being of sound mind, wilfully and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below and do hereby declare:

1. If at any time I should have an incurable injury, disease or illness certified to be a terminal condition by two physicians, one of whom is the attending physician, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.

2. In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

3. I have been diagnosed and notified at least 14 days ago as having a terminal condition by _____, M.D., whose address is _____, and whose telephone number is _____. I understand that if I have not filled in the physician's name and address, it shall be presumed that I did not have a terminal condition when I made out this directive.

4. This directive shall have no force or effect five years from the date filled in above.

5. I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

Signed _____

City, County and State of Residence _____

I hereby witness this directive and attest that:

(1) I personally know the Declarant and believe the Declarant to be of sound mind.

(2) To the best of my knowledge, at the time of the execution of this directive, I:

(a) Am not related to the Declarant by blood or marriage,

(b) Do not have any claim on the estate of the Declarant,

(c) Am not entitled to any portion of the Declarant's estate by any will or by operation of law, and

(d) Am not a physician attending the Declarant or a person employed by a physician attending the Declarant.

(3) I understand that if I have not witnessed this directive in good faith I may be responsible for any damages that arise out of giving this directive its intended effect.

Witness _____

Witness _____

---

(2) A directive made pursuant to subsection (1) of this section is only valid if signed by the declarant in the presence of two attesting witnesses who, at the time the directive is executed, are not:

(a) Related to the declarant by blood or marriage; or

(b) Entitled to any portion of the estate of the declarant upon his decease under any will or codicil of the declarant or by operation of law at the time of the execution of the directive; or

(c) The attending physician or an employee of the attending physician or of a health facility in which the declarant is a patient; or

(d) Persons who at the time of the execution of the directive have a claim against any portion of the estate of the declarant upon the declarant's decease.

(3) One of the witnesses, if the declarant is a patient in a house for the aged licensed under ORS chapter 442 at the time the directive is executed, shall be an individual designated by the Department of Human Resources for the purpose of

determining that the declarant is not so insulated from the voluntary decision-making role that the declarant is not capable of wilfully and voluntarily executing a directive.

(4) A witness who does not attest a directive in good faith shall be liable for any damages that arise from giving effect to an invalid directive.

(5) A directive made pursuant to ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 may be revoked at any time by the declarant without regard to his mental state or competency by any of the following methods:

(a) By being burned, torn, canceled, obliterated or otherwise destroyed by the declarant or by some person in his presence and by his direction.

(b) By a written revocation of the declarant expressing his intent to revoke, signed and dated by the declarant.

(c) By a verbal expression by the declarant of his intent to revoke the directive.

(6) Unless revoked, a directive shall be effective for five years from the date of execution. If the declarant has executed more than one directive, such time shall be determined from the date of execution of the last directive known to the attending physician. If the declarant becomes comatose or is rendered incapable of communicating with the attending physician, the directive shall remain in effect for the duration of the comatose condition or until such time as the declarant's condition renders him able to communicate with the attending physician.

§ 97.060 Validity of directive as to physician.

A directive that is valid on its face is valid as to any physician for the purposes of ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 unless the physician has actual knowledge of facts that render the directive invalid or is under the direction of a court not to give effect to the directive.

§ 97.065 Effect of directive.

(1) It shall be lawful for an attending physician or a licensed health professional under the direction of an attending physician, acting in good faith and in accordance with the requirements of ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990, to withhold or withdraw life-sustaining procedures from a qualified patient who has properly executed a directive in accordance with the requirements of ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990.

(2) A physician or licensed health professional or health facility under the direction of a physician who, acting in good faith and in accordance with the requirements of ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990, causes the withholding or withdrawal of life-sustaining procedures shall not be guilty of any criminal offense, shall not be subject to civil

liability and shall not be in violation of any professional oath, affirmation or standard of care.

(3) A physician or licensed health professional or health facility shall not be guilty of any criminal offense, shall not be subject to civil liability and shall not be in violation of any professional oath, affirmation or standard of care for failing to assume the duties created by or for failing to give effect to any directive or revocation made pursuant to ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 unless that physician has actual knowledge of the directive or revocation.

§ 97.070 Duties created by directive.

(1) Except as provided in this section, no physician, licensed health professional or medical facility shall be under any duty, whether by contract, by statute or by any other legal requirement to participate in the withdrawal or withholding of life-sustaining procedures.

(2) (a) An attending physician shall make a directive or a copy of a directive made pursuant to ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 part of the patient's medical record.

(3) A physician or medical facility electing for any reason not to participate in the withholding or withdrawal of life-sustaining procedures in accord with a directive made pursuant to ORS 97.050 to 97.090 and subsections (5) and (7) of 97.990 shall:

(a) Make a reasonable effort to locate a physician or medical facility that will give effect to a qualified patient's directive and shall have a duty to transfer the qualified patient to that physician or facility; or

(b) At the request of a patient or of the patient's family, a physician or medical facility shall transfer the patient to another physician or medical facility that will reconsider circumstances which might make ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 applicable to the patient.

§ 97.075 Procedure prior to withdrawal of life-sustaining procedures.

(1) Before withdrawing or withholding life-sustaining procedures from a qualified patient who is mentally competent in the opinion of the attending physician, the attending physician shall determine that the directive is valid under the requirements of ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 and shall determine that all steps proposed to be taken are in accord with the desires of the qualified patient.

(2) Before withdrawing or withholding life-sustaining procedures from a qualified patient who is not mentally competent in the opinion of the attending physician, the attending physician shall determine that the directive is valid under the requirements of ORS 97.050 to 97.090 and subsections (5) to (7)

of 97.990 and shall weigh the directive with other surrounding circumstances such as information from the affected family or the nature of the patient's illness, injury or disease to determine if the steps proposed to be taken are, in the opinion of the attending physician, in accord with the known desires of the qualified patient. If the declarant was a qualified patient at least 14 days before executing or reexecuting the directive, the directive shall be conclusively presumed, unless revoked, to be in accord with the desires of the qualified patient for the purposes of this subsection.

§ 97.080 Effect of directive on insurance.

(1) Except as provided in subsection (2) of this section, the making of a directive pursuant to ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 shall not restrict, inhibit or impair in any manner the sale, procurement or issuance of any policy of insurance, nor shall it be deemed to modify the terms of an existing policy of insurance.

(2) No physician, health facility, health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, nonprofit hospital service plan or other direct or indirect health service provider shall require any person to execute a directive as a condition for being insured for, or receiving, health care services.

(3) No policy of insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient.

§ 97.085 Construction of ORS 97.050 to 97.090 concerning mercy killing, exclusiveness and suicide.

(1) Nothing in ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 shall be construed to condone, authorize or approve mercy killing, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying as provided in ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990.

(2) Nothing in ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 are cumulative.

(3) The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of ORS 97.050 to 97.090 and subsections (5) to (7) of 97.990 shall not, for any purpose, constitute a suicide.

§ 97.090 Prohibited acts.

(1) No person shall by willfully concealing or destroying a revocation or by willfully falsifying or forging a directive cause the withdrawal or withholding of life-sustaining procedures.

(2) No person shall by willfully concealing or destroying a directive or by willfully falsifying or forging a revocation cause an individual's intent with respect to the withholding or withdrawal of life-sustaining procedures not to be given effect.

Or. Rev. Stat. §§ 97.050 through 97.090 (June 9, 1977).

Texas

§ 1. Short title.

This Act shall be known and may be cited as the Natural Death Act.

§ 2. Definitions.

In this Act:

(1) "Attending physician" means the physician selected by, or assigned by the physician selected by, the patient who has primary responsibility for the treatment and care of the patient.

(2) "Directive" means a written document voluntarily executed by the declarant in accordance with the requirements of Section 3 of this Act. The directive, or a copy of the directive, shall be made part of the patient's medical records.

(3) "Life-sustaining procedure" means a medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physician, noted in the qualified patient's medical records, death is imminent whether or not such procedures are utilized. "Life-sustaining procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain.

(4) "Physician" means a physician and surgeon licensed by the Texas State Board of Medical Examiners.

(5) "Qualified patient" means a patient diagnosed and certified in writing to be afflicted with a terminal condition by two physicians, one of whom shall be the attending physician, and the other shall be chosen by the patient or the attending physician, who have each personally examined the patient.

(6) "Terminal condition" means an incurable condition caused by injury, disease, or illness, which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serves only to postpone the moment of death of the patient.

§ 3. Directive for withholding or withdrawal of life-sustaining procedures in event of terminal condition.

Any adult person may execute a directive for the withholding or withdrawal of life-sustaining procedures in the event of a terminal condition. The directive shall be signed by the declarant in the presence of two witnesses not related to the declarant by blood or marriage and who would not be entitled to any portion of the estate of the declarant on his decease under any will of the declarant or codicil thereto or by operation of law. In addition, a witness to a directive shall not be the attending physician, an employee of the attending physician or a health facility in which the declarant is a patient, a patient in a health care facility in which the declarant is a patient, or any person who has a claim against any portion of the estate of the declarant upon his decease at the time of the execution of the directive. The signature of the declarant shall be acknowledged, and the witnesses shall subscribe and swear to the directive before a notary public. The directive shall be in the following form:

"DIRECTIVE TO PHYSICIANS

"Directive made this _____ day of _____ (month, year).

"I, _____, being of sound mind, willfully and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, and do hereby declare:

"1. If at any time I should have an incurable condition caused by injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my attending physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.

"2. In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physicians as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

"3. If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.

"4. I have been diagnosed and notified as having a terminal condition by _____, M.D., whose address is _____ and whose telephone number is _____. I understand that if I have not filled in the physician's name and

address, it shall be presumed that I did not have a terminal condition when I made out this directive.

"5. This directive shall be in effect until it is revoked.

"6. I understand the full import of this directive and I am emotionally and mentally competent to make this directive.

"7. I understand that I may revoke this directive at any time.

"Signed _____

City, County, and State of Residence _____

The declarant has been personally known to me and I believe him or her to be of sound mind. I am not related to the declarant by blood or marriage, nor would I be entitled to any portion of the declarant's estate on his decease, nor am I the attending physician of declarant or an employee of the attending physician or a health facility in which declarant is a patient, or a patient in the health care facility in which the declarant is a patient, or any person who has a claim against any portion of the estate of the declarant upon his decease.

"Witness _____

"Witness _____

"STATE OF TEXAS

COUNTY OF _____

"Before me, the undersigned authority, on this day personally appeared _____, _____, and _____, known to me to be the declarant and witnesses whose names are subscribed to the foregoing instrument in their respective capacities, and, all of said persons being by me duly sworn, the declarant, _____, declared to me and to the said witnesses in my presence that said instrument is his Directive to Physicians, and that he had willingly and voluntarily made and executed it as his free act and deed for the purposes therein expressed.

"Declarant _____

"Witness _____

"Witness _____

"Subscribed and acknowledged before me by the said Declarant, _____, and by the said witnesses, _____ and _____, on this _____ day of _____, 19_____.

_____

Notary Public in and for

_____

County, Texas"

§ 4. Revocation of directive.

(a) A directive may be revoked at any time by the declarant, without regard to his mental state or competency, by any of the following methods:

1. by being canceled, defaced, obliterated, or burnt, torn, or otherwise destroyed by the declarant or by some person in his presence and by his direction;

2. by a written revocation of the declarant expressing his intent to revoke, signed and dated by the declarant. Such revocation shall become effective only on communication to an attending physician by the declarant or by a person acting on behalf of the declarant or by mailing said revocation to an attending physician. An attending physician or his designee shall record in the patient's medical record the time and date when he received notification of the written revocation and shall enter the word "VOID" on each page of the copy of the directive in the patient's medical records; or

3. by a verbal expression by the declarant of his intent to revoke the directive. Such revocation shall become effective only on communication to an attending physician by the declarant or by a person acting on behalf of the declarant. An attending physician or his designee shall record in the patient's medical record the time, date, and place of the revocation and the time, date, and place, if different, of when he received notification of the revocation and shall enter the word "VOID" on each page of the copy of the directive in the patient's medical records.

(b) Except as otherwise provided in this Act, there shall be no criminal or civil liability on the part of any person for failure to act on a revocation made pursuant to this section unless that person has actual knowledge of the revocation.

§ 5. Duration of directive.

A directive shall be effective until it is revoked in a manner prescribed in Section 4 of this Act. Nothing in this Act shall be construed to prevent a declarant from reexecuting a directive at any time in accordance with the formalities of Section 3 of this Act, including reexecution subsequent to a diagnosis of a terminal condition. If the declarant has executed more than one directive, such time shall be determined from the date of execution of the last directive known to the attending physician. If the declarant becomes comatose or is rendered incapable of communicating with the attending physician, the directive shall remain in effect for the duration of the comatose condition or until such time as the declarant's condition renders him or her able to communicate with the attending physician.

§ 6. Civil or criminal liability.

No physician or health facility which, acting in accordance with the requirements of this Act, causes the withholding or withdrawal of life-sustaining procedures from a qualified patient, shall be subject to civil liability therefrom unless negligent. No health professional, acting under the direction of a physician, who participates in the withholding or withdrawal

of life-sustaining procedures in accordance with the provisions of this Act shall be subject to any civil liability unless negligent. No physician, or health professional acting under the direction of a physician, who participates in the withholding or withdrawal of life-sustaining procedures in accordance with the provisions of this Act shall be guilty of any criminal act or of unprofessional conduct unless negligent. No physician, health care facility, or health care professional shall be liable either civilly or criminally for failure to act pursuant to the declarant's directive where such physician, health care facility, or health care professional had no knowledge of such directive.

§ 7. Failure to execute directive.

(a) Prior to effecting a withholding or withdrawal of life-sustaining procedures from a qualified patient pursuant to the directive, the attending physician shall determine that the directive complies with the form of the directive set out in Section 3 of this Act, and, if the patient is mentally competent, that the directive and all steps proposed by the attending physician to be undertaken are in accord with the existing desires of the qualified patient and are communicated to the patient.

(b) If the declarant was a qualfied patient prior to executing or reexecuting the directive, the directive shall be conclusively presumed, unless revoked, to be the directions of the patient regarding the withholding or withdrawal of life-sustaining procedures. No physician, and no health professional acting under the direction of a physician, shall be criminally or civilly liable for failing to effectuate the directive of the qualified patient pursuant to this subsection. A failure by a physician to effectuate the directive of a qualified patient pursuant to this subsection may constitute unprofessional conduct if the physician refuses to make the necessary arrangements or fails to take the necessary steps to effect the transfer of the qualified patient to another physician who will effectuate the directive of the qualified patient.

(c) If the declarant becomes a qualified patient subsequent to executing the directive, and has not subsequently reexecuted the directive, the attending physician may give weight to the directive as evidence of the patient's directions regarding the withholding or withdrawal of life-sustaining procedures and may consider other factors, such as information from the affected family or the nature of the patient's illness, injury, or disease, in determining whether the totality of circumstances known to the attending physician justifies effectuating the directive. No physician, and no health professional acting under the direction of a physician, shall be criminally or civilly liable for failing to effectuate the directive of the qualified patient pursuant to this subsection.

§ 8. Effect on offense of aiding suicide and insurance policies.

(a) The withholding or withdrawal of life-sustaining procedures from a qualified patient in accordance with the provisions of this Act shall not, for any purpose, constitute an offense under Section 22.08, Penal Code.

(b) The making of a directive pursuant to Section 3 of this Act shall not restrict, inhibit, or impair in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary.

(c) No physician, health facility, or other health provider, and no health care service plan, or insurer issuing insurance, may require any person to execute a directive as a condition for being insured for, or receiving, health care services nor may the execution or failure to execute a directive be considered in any way in establishing the premiums for insurance.

§ 9. Tampering with directive.

A person who willfully conceals, cancels, defaces, obliterates, or damages the directive of another without such declarant's consent shall be guilty of a Class A misdemeanor. A person who falsifies or forges the directive of another, or willfully conceals or withholds personal knowledge of a revocation as provided in Section 4 of this Act, with the intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarant, and thereby, because of any such act, directly causes life-sustaining procedures to be withheld or withdrawn and death to thereby be hastened, shall be subject to prosecution for criminal homicide under the provisions of the Penal Code.

§ 10. Mercy killing not condoned.

Nothing in this Act shall be construed to condone, authorize, or approve mercy killing, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying as provided in this Act.

§ 11. Act as cumulative.

Nothing in this Act shall impair or supersede any legal right or legal responsibility which any person may have to effect the withholding or withdrawal of life-sustaining procedures in any lawful manner. In such respect the provisions of this Act are cumulative.

Tex. Rev. Civ. Stat. Ann. art. 4590h (August 29, 1977).

Vermont

§ 1. 18 V.S.A. Chapter 111 is added to read:

§ 5251. Purpose and policy.

The state of Vermont recognizes that a person as a matter of right may rationally make an election as to the extent of medical treatment he will receive in the event that his physical state reaches such a point of deterioration that he is in a terminal state and there is no reasonable expectation that life can be continued with dignity and without pain. A person has a fundamental right to determine whether or not life sustaining procedures which would cause prolongation of life beyond natural limits, should be used or withdrawn.

§ 5252. Definitions.

The following definitions shall be applicable in the construction of this chapter:

(1) "Attending physician" means the physician selected by, or assigned to the patient, who has primary responsibility for the treatment and care of the patient.

(2) "Extraordinary measures" means any medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function which, in the judgment of the attending physician, when applied to the patient, would serve only to artificially postpone the moment of death and where, in the judgment of the attending physician, the patient is in a terminal state.

(3) "Terminal care document" means a document which, when duly executed, contains the express direction that no extraordinary measures be taken when the person executing said document is in a terminal state, without hope of recovery from such state and is unable to actively participate in the decision-making process.

(4) "Physician" means a medical doctor licensed to practice in the state of Vermont.

(5) "Terminal state" means an incurable condition causd by injury, disease or illness which regardless of the application of life-saving procedures would, within reasonable medical judgment, produce death and where application of life-sustaining procedures would only postpone the moment of death.

§ 5253. Terminal care document.

A person of sound mind who is 18 years of age or older may execute at any time a document commonly known as a terminal care document, directing that no extraordinary measures be used to prolong his life when he is in a terminal state. The document shall only be effective in the event that the person is incapable of participating in decisions about his care and may, but need not, be in form and substance substantially as follows:

"To my family, my physician, my lawyer, my clergyman. To any medical facility in whose care I happen to be. To any individual who may become responsible for my health, welfare or affairs.

"Death is as much a reality as birth, growth, maturity and old age—it is the one certainty of life. If the time comes when I, _____, can no longer take part in decisions of my own future, let this statement stand as an expression of my wishes, while I am still of sound mind.

"If the situation should arise in which I am in a terminal state and there is no reasonable expectation of my recovery, I direct that I be allowed to die a natural death and that my life not be prolonged by extraordinary measures. I do, however, ask that medication be mercifully administered to me to alleviate suffering even though this may shorten my remaining life.

"This statement is made after careful consideration and is in accordance with my strong convictions and beliefs. I want the wishes and directions here expressed carried out to the extent permitted by law. Insofar as they are not legally enforceable, I hope that those to whom this will is addressed will regard themselves as morally bound by these provisions.

Signed: _____

Date: _____

Witness: _____

Witness: _____

Copies of this request have been given to:"

_____

_____

_____

§ 5254. Execution and witnesses.

The document set forth in section 5253 shall be executed by the person making the same in the presence of two or more subscribing witnesses, none of whom shall be the person's spouse, heir, attending physician or person acting under the direction or control of the attending physician or any other person who has at the time of the witnessing thereof any claims against the estate of the person.

§ 5256. Action by physician.

An attending physician and any other physician under his direction or control, having in his possession his patient's terminal care document, or having knowledge that such a duly executed document is part of the patient's record in the institution in which he is receiving care, shall be bound to follow as closely as possible the dictates of said document. However, if because of moral conflict with the spirit of this act, a physician finds it impossible to follow his patient's directions, he shall forthwith have a duty to so inform his patient or

actively assist in selecting another physician who is willing to honor the patient's directions, or both.

§ 5257. Revocation.

A person who has validly executed a document consistent with the provisions of sections 5253 and 5254 may revoke the same orally in the presence of two or more witnesses, at least one of whom shall not be a spouse or a relative as specified in 15 V.S.A. §§ 1 or 2, or by burning, tearing or obliterating the same or by causing the same to be done by some other person at his direction and in his presence. A terminal care document may be revoked only as provided herein.

§ 5258. Duty to deliver.

Any person having in his possession a duly executed terminal care document, if it becomes known to him that the person executing the same is in such circumstances that the terms of the terminal care document might become applicable, shall forthwith deliver the same to the physician attending the person executing said document or to the hospital in which said person is a patient.

§ 5259. Immunity.

An attending physician, other physician, nurse, health professional or any other person acting for him or under his control, or hospital within which the person may be, shall forever be immune from any civil or criminal liability for any act or intentional failure to act if said act or intentional failure to act is done pursuant to the terminal care document.

§ 5260. Suicide.

The withholding or withdrawal of life-sustaining procedures from a patient who has executed a document consistent with the purposes of section 5253 shall at no time be construed as a suicide for any legal purpose.

§ 5261. Freedom from influence.

No physician, health facility, or other health provider, and no health care service plan, insurer issuing disability insurance, self-insured employee, welfare benefit plan, or nonprofit hospital service plan, shall require any person to execute a terminal care document as a condition for being insured for, or receiving, health care services; nor can health care or services be refused except as is hereinbefore provided because a person is known to have executed a terminal care document.

§ 5262. Presumptions.

This chapter shall not be construed to create a presumption that in the absence of a terminal care document, a person wants extraordinary measures to be taken.

§ 2. 13 V.S.A. §1801 is amended to read:

§ 1801. Forgery and counterfeiting of papers, documents, etc.

A person who wittingly, falsely and deceitfully makes, alters, forges or counterfeits, or wittingly, falsely or deceitfully causes to be made, altered, forged or counterfeited, or procures, aids or counsels the making, altering, forging or counterfeiting, of a writ, process, public record, or any certificate, return or attestation of a clerk of a court, public register, notary public, justice or other public officer, in relation to a matter wherein such certificate, return or attestation may be received as legal proof, or a charter, deed, or any evidence or muniment of title to property, will, terminal care document, testament, bond, or writing obligatory, letter of attorney, policy of insurance, bill of lading, bill of exchange, promissory note, or an order drawn on a person or corporation, or on a state, county or town or school district treasurer, for money or other property, or an acquittance or discharge for money or other property, or an acceptance of a bill of exchange, or endorsement or assignment of a bill of exchange or promissory note, for the payment of money, or any accountable receipt for money, goods or other property, or certificate of stock, with intent to injure or defraud a person, shall be imprisoned not more than ten years and fined not more than $1,000.00.

§ 3. Effective date.

This act shall take effect from passage.

Vt. Stat. Ann. tit. 18, §§ 5251 through 5262 and tit. 13, § 1801 (April 8, 1982).

Virginia

§ 54-325.8:1. Policy statement; short title.

The General Assembly finds that all competent adults have the fundamental right to control the decisions relating to their own medical care, including the decision to have medical or surgical means or procedures calculated to prolong their lives provided, withheld or withdrawn.

The General Assembly further finds that the artificial prolongation of life for persons with a terminal condition may cause loss of individual dignity and secure only a precarious and burdensome existence, while providing nothing medically necessary or beneficial to the patient.

In order that the dignity, privacy and sanctity of persons with such conditions may be respected even after they are no longer able to participate actively in decisions concerning themselves, the General Assembly hereby declares that the laws of the Commonwealth of Virginia shall recognize the right of a competent adult to make an oral or written declaration instructing his physician to withhold or withdraw life-prolong-

ing procedures or to designate another to make the treatment decision for him, in the event such person is diagnosed as suffering from a terminal condition.

The provisions of this article shall be known and may be cited as the "Natural Death Act of Virginia."

§ 54-325.8:2. Definitions.

As used in this Act:

"Attending physician" means the primary physician who has responsibility for the treatment and care of the patient.

"Declaration" means (i) a witnessed document in writing, voluntarily executed by the declarant in accordance with the requirements of § 54-325.8:3 or (ii) a witnessed oral statement, made by the declarant subsequent to the time he is diagnosed as suffering from a terminal condition and in accordance with the provisions of § 54-325.8:3.

"Life-prolonging procedure" means any medical procedure, treatment or intervention which (i) utilizes mechanical or other artificial means to sustain, restore or supplant a spontaneous vital function or is otherwise of such a nature as to afford a patient no reasonable expectation of recovery from a terminal condition and (ii) when applied to a patient in a terminal condition, would serve only to prolong the dying process. "Life-prolonging procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to provide comfort care or to alleviate pain.

"Physician" means a person licensed to practice medicine in the Commonwealth of Virginia.

"Qualified patient" means a patient who has (i) made a declaration in accordance with this Act and (ii) been diagnosed and certified in writing by the attending physician, (and, in any case where the patient is comatose, incompetent or otherwise physically or mentally incapable of communication, by one other physician who has examined the patient) to be afflicted with a terminal condition.

"Terminal condition" means a condition caused by injury, disease or illness from which, to a reasonable degree of medical certainty, (i) there can be no recovery and (ii) death is imminent.

"Witness" means a person who is not a spouse or blood relative of the patient.

§ 54-325.8:3. Procedure for making a declaration; notice to physician.

Any competent adult may, at any time, make a written declaration directing the withholding or withdrawal of life-prolonging procedures in the event such person should have a terminal condition. A written declaration shall be signed by the declarant in the presence of two subscribing witnesses. An

oral declaration may be made by a competent adult in the presence of a physician and two witnesses by any nonwritten means of communication at any time subsequent to the diagnosis of a terminal condition.

It shall be the responsibility of the declarant to provide for notification to his attending physician that a declaration has been made. In the event the declarant is comatose, incompetent or otherwise mentally or physically incapable, any other person may notify the physician of the existence of a declaration. An attending physician who is so notified shall promptly make the declaration or a copy of the declaration, if written, a part of the declarant's medical records. If the declaration is oral, the physician shall likewise promtly make the fact of such declaration a part of the patient's medical record.

§ 54-325.8:4. Suggested form of written declaration.

A declaration executed pursuant to this Act may, but need not, be in the following form, and may include other specific directions including, but not limited to, a designation of another person to make the treatment decision for the declarant should he be (i) diagnosed as suffering from a terminal condition and (ii) comatose, incompetent or otherwise mentally or physically incapable of communication. Should any other specific directions be held to be invalid, such invalidity shall not affect the declaration.

Declaration made this _____ day of _____ (month/year), I _____ willfully and voluntarily make known my desire that my dying shall not be artificially prolonged under the circumstances set forth below, and do hereby declare:

If at any time I should have a terminal condition and my attending physician has determined that there can be no recovery from such condition and my death is imminent, where the application of life-prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

In the absence of my ability to give directions regarding the use of such life-prolonging procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences of such refusal.

I understand the full import of this declaration and I am emotionally and mentally competent to make this declaration.

_____

(Signed)

The declarant is known to me and I believe him or her to be of sound mind.

_____
Witness

_____
Witness

§ 54-325.8:5. Revocation of declaration.

A declaration may be revoked at any time by the declarant (i) by a signed, dated writing; or (ii) by physical cancellation or destruction of the declaration by the declarant or another in his presence and at his direction; or (iii) by an oral expression of intent to revoke. Any such revocation shall be effective when comunicated to the attending physician. No civil or criminal liability shall be imposed upon any person for a failure to act upon a revocation unless that person has actual knowledge of such revocation.

§ 54-325.8:6. Procedure in absence of declaration; no presumption.

Nothing in this Act shall be construed in any manner to prevent the withholding or the withdrawal of life-prolonging procedures from an adult patient with a terminal condition who (i) is comatose, incompetent or otherwise physically or mentally incapable of communication and (ii) has not made a declaration in accordance with this Act, provided there is consultation and agreement for the withholding or the withdrawal of life-prolonging procedures between the attending physician and any of the following individuals, in the following order of priority if no individual in a prior class is reasonably available, willing and competent to act:

1. The judicially appointed guardian or committee of the person of the patient if one has been appointed. This paragraph shall not be construed to require such appointment in order that a treatment decision can be made under this section;

2. The person or persons designated by the patient in writing to make the treatment decision for him should he be diagnosed as suffering from a terminal condition; or

3. The patient's spouse; or

4. An adult child of the patient or, it the patient has more than one adult child, by a majority of the children who are reasonably available for consultation; or

5. The parents of the patient; or

6. The nearest living relative of the patient.

In any case where the treatment decision is made by a person specified in paragraph 3, 4, 5, or 6, there shall be at least two witnesses present at the time of the consultation when the treatment decision is made.

The absence of a declaration by an adult patient shall not give rise to any presumption as to his intent to consent to or refuse life-prolonging procedures.

§ 54-325.8:7. Transfer of patient.

An attending physician who refuses to comply with the declaration of a qualified patient or the treatment decision of a person designated to make the decision (i) by the declarant in his declaration or (ii) pursuant to § 58-325.8:6 shall make a reasonable effort to transfer the patient to another physician.

§ 54-325.8:8. Immunity from liability; burden of proof; presumption.

A health care facility, physician or other person acting under the direction of a physician shall not be subject to criminal prosecution or civil liability or be deemed to have engaged in unprofessional conduct as a result of the withholding or the withdrawal of life-prolonging procedures from a patient with a terminal condition in accordance with this Act. A person who authorizes the withholding or withdrawal of life-prolonging procedures from a patient with a terminal condition in accordance with a qualified patient's declaration or as provided in § 54-325.8:6 shall not be subject to criminal prosecution or civil liability for such action.

The provisions of this section shall apply unless it is shown by a preponderance of the evidence that the person authorizing or effectuating the withholding or withdrawal of life-prolonging procedures did not, in good faith, comply with the provisions of this Act. A declaration made in accordance with this Act shall be presumed to have been made voluntarily.

§ 54-325.8:9. Willful destruction, concealment, etc. of declaration or revocation; penalties.

Any person who willfully conceals, cancels, defaces, obliterates, or damages the declaration of another without the declarant's consent or who falsifies or forges a revocation of the declaration of another, thereby causing life-prolonging procedures to be utilized in contravention of the previously expressed intent of the patient shall be guilty of a Class 6 felony.

Any person who falsifies or forges the declaration of another, or willfully conceals or withholds personal knowledge of the revocation of a declaration, with the intent to cause a withholding or withdrawal of life-prolonging procedures, contrary to the wishes of the declarant, and thereby, because of such act, directly causes life-prolonging procedures to be withheld or withdrawn and death to be hastened, shall be guilty of a Class 2 felony.

§ 54-325.8:10. Mercy killing or euthanasia prohibited.

Nothing in this Act shall be construed to condone, authorize or approve mercy killing or euthanasia, or to permit

any affirmative or deliberate act or omission to end life other than to permit the natural process of dying.

§ 54-325.8:11. Effect of declaration; suicide; insurance; declarations executed prior to effective date.

The withholding or withdrawal of life-prolonging procedures from a qualified patient in accordance with the provisions of this Act shall not, for any purpose, constitute a suicide. Nor shall the making of a declaration pursuant to this Act effect the sale, procurement or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally imparied or invalidated by the withholding or withdrawal of life-prolonging procedures from an insured qualified patient, notwithstanding any term of the policy to the contrary. A person shall not be required to make a declaration as a condition for being insured for, or receiving, health care services.

The declaration of any qualified patient made prior to the effective date of this Act shall be given effect as provided in this Act.

§ 54-325.8:12. Preservation of existing rights.

The provisions of this Act are cumulative with existing law regarding an individual's right to consent or refuse to consent to medical treatment and shall not impair any existing rights or responsibilities which a health care provider, a patient, including a minor or incompetent patient, or a patient's family may have in regard to the withholding or withdrawal of life-prolonging medical procedures under the common law or statutes of the Commonwealth.

§ 54-325.8:13. Severability.

If any provision of this Act is held invalid, such invalidity shall not affect other provisions of the Act which can be given effect without the invalid provision. To this end, the provisions of this Act are severable.

Passed by the Virginia Assembly Feb. 1983, awaiting Governor's signature as of March 17, 1983.

Washington

§ 70.122.010 Legislative findings.

The legislature finds that adult persons have the fundamental right to control the decisons relating to the rendering of their own medical care, including the decision to have life-sustaining procedures withheld or withdrawn in instances of a terminal condition.

The legislature further finds that modern medical technology has made possible the artificial prolongation of human life beyond natural limits.

The legislature further finds that, in the interes of protecting individual autonomy, such prolongation of life for persons with a terminal condition may cause loss of patient dignity, and unnecessary pain and suffering, while providing nothing medically necessary or beneficial to the patient.

The legislature further finds that there exists considerable uncertainty in the medical and legal professions as to the legality of terminating the use or application of life-sustaining procedures where the patient has voluntarily and in sound mind evidenced a desire that such procedures be withheld or withdrawn.

In recognition of the dignity and privacy which patients have a right to expect the legislature hereby declares that the laws of the state of Washington shall recognize the right of an adult person to make a written directive instructing such person's physician to withhold or withdraw life-sutaining procedures in the event of a terminal condition.

§ 70.122.020 Definitions.

Unless the context clearly requires otherwise, the definitions contained in this section shall apply throughout this chapter.

(1) "Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

(2) "Directive" means a written document voluntarily executed by the declarer in accordance with the requirements of RCW 70.122.030.

(3) "Health facility" means a hospital as defined in RCW 70.38.020(7) or a nursing home as defined in RCW 70.38.020(8).

(4) "Life-sustaining procedure" means any medical or surgical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physician, death is imminent whether or not such procedures are utilized. "Life-sustaining procedure" shall not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain.

(5) "Physician" means a person licensed under chapters 18.71 or 18.57 RCW.

(6) "Qualified patient" means a patient diagnosed and certified in writing to be afflicted with a terminal condition by two physicians one of whom shall be the attending physician, who have personally examined the patient.

(7) "Terminal condition" means an incurable condition caused by injury, disease, or illness, which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures serve only to postpone the moment of death of the patient.

(8) "Adult person" means a person attaining the age of majority as defined in RCW 26.28.010 and 26.28.015.

§ 70.122.030 Directive to withhold or withdraw life-sustaining procedures.

(1) Any adult person may execute a directive directing the withholding or withdrawal of life-sustaining procedures in a terminal condition. The directive shall be signed by the declarer in the presence of two witnesses not related to the declarer by blood or marriage and who would not be entitled to any portion of the estate of the delcarer upon declarer's decease under any will of the declarer or codicil thereto then existing or, at the time of the directive, by operation of law then existing. In addition, a witness to a directive shall not be the attending physician, an employee of the attending physician or a health facility in which the declarer is a patient, or any person who has a claim against any portion of the estate of the declarer upon declarer's decease at the time of the execution of the directive. The directive, or a copy thereof, shall be made part of the patient's medical records retained by the attending physician, a copy of which shall be forwarded to the health facility upon the withdrawal of life-sustaining procedures. The directive shall be essentially in the following form, but in addition may include other specific directions:

DIRECTIVE TO PHYSICIANS

Directive made this _____ day of _____ (month, year). I _____, being of sound mind, wilfully, and voluntarily make known my desire that my life shall not be artificially prolonged under the circumstances set forth below, and do hereby declare that:

(a) If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians, and where the application of life-sustaining procedures would serve only to artificially prolong the moment of my death and where my physician determines that my death is imminent whether or not life-sustaining procedures are utilized, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally.

(b) In the absence of my ability to give directions regarding the use of such life-sustaining procedures, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse

medical or surgical treatment and I accept the consequences from such refusal.

(c) If I have been diagnosed as pregnant and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.

(d) I understanding the full import of this directive and I am emotionally and mentally competent to make this directive.

Signed _____

City, County, and State of Residence _____

The declarer has been personally known to me and I believe him or her to be of sound mind.

Witness _____

Witness _____

(2) Prior to effectuating a directive the diagnosis of a terminal condition by two physicians shall be verified in writing, attached to the directive, and made a permanent part of the patient's medical records.

§ 70.122.040 Revocation of directive.

(1) A directive may be revoked at any time by the declarer, without regard to declarer's mental state or competency, by any of the following methods:

(a) By being canceled, defaced, obliterated, burned, torn, or otherwide destroyed by the declarer or by some person in declarer's presence and by declarer's direction.

(b) By a written revocation of the declarer expressing declarer's intent to revoke, signed, and dated by the declarer. Such revocation shall become effective only upon communication to the attending physician by the declarer or by a person acting on behalf of the declarer. The attending physician shall record in the patient's medical record the time and date when said physician received notification of the written revocation.

(c) By a verbal expression by the declarer of declarer's intent to revoke the directive. Such revocation shall become effective only upon communication to the attending physician by the declarer or by a person acting on behalf of the declarer. The attending physician shall record in the patient's medical record the time, date, and place of the revocation and the time, date, and place, if different, of when said physician received notification of the revocation.

(2) There shall be no criminal or civil liability on the part of any person for failure to act upon a revocation made pursuant to this section unless that person has actual or constructive knowledge of the revocation.

(3) If the declarer becomes comatose or is rendered incapable of communicating with the attending physician, the directive shall remain in effect for the duration of the comatose

condition or until such time as the declarer's condition renders declarer able to communicate with the attending physician.

§ 70.122.050 Liability of health personnel, facilities.

No physician or health facility which, acting in good faith in accordance with the requirements of this chapter, causes the withholding or withdrawal of life-sustaining procedures from a qualified patient, shall be subject to civil liability therefrom. No licensed health personnel, acting under the direction of a physician, who participates in good faith in the withholding or withdrawal of life-sustaining procedures in accordance with the provisions of this chapter shall be subject to any civil liability. No physician, or licensed health personnel acting under the direction of a physician, who participates in good faith in the withholding or withdrawal of life-sustaining procedures in accordance with the provisions of this chapter shall be guilty of any criminal act or of unprofessional conduct.

§ 70.122.060 Procedures by physician.

(1) Prior to effectuating a withholding or withdrawal of life-sustaining procedures from a qualified patient pursuant to the directive, the attending physician shall make a reasonable effort to determine that the directive complies with RCW 70.122.030 and, if the patient is mentally competent, that the directive and all steps proposed by the attending physician to be undertaken are currently in accord with the desires of the qualified patient.

(2) The directive shall be conclusively presumed, unless revoked, to be the directions of the patient regarding the withholding or withdrawal of life-sustaining procedures. No physician, and no licensed health personnel acting in good faith under the direction of a physician, shall be criminally or civilly liable for failing to effectuate the directive of the qualified patient pursuant to this subsection. If the physician refuses to effectuate the directive, such physician shall make a good faith effort to transfer the qualified patient to another physician who will effectuate the directive of the qualified patient.

§ 70.122.070 Effects of carrying out directive—insurance.

(1) The withholding or withdrawal of life-sustaining procedures from a qualified patient pursuant to the patient's directive in accordance with the provisions of this chapter shall not, for any purpose, consitute a suicide.

(2) The making of a directive pursuant to RCW 70.122.030 shall not restrict, inhibit, or impair in any manner the sale, procurement, or issuance of any policy of life insurance, nor shall it be deemed to modify the terms of an existing policy of life insurance. No policy of life insurance shall be legally impaired or invalidated in any manner by the withholding or withdrawal of life-sustaining procedures from an insured

qualified patient, notwithstanding any term of the policy to the contrary.

(3) No physician, health facility, or other health provider, and no health care service plan, insurer issuing disability insurance, self-insured employee welfare benefit plan, or nonprofit hospital service plan, shall require any person to execute a directive as a condition for being insured for, or receiving, health care services.

§ 70.122.080 Effects of carrying out directive on cause of death.

The act of withholding or withdrawing life-sustaining procedures when done pursuant to a directive described in RCW 70.122.030 and which causes the death of the declarer, shall not be construed to be an intervening force or to affect the chain of proximate cause between the conduct of any person that placed the declarer in a terminal condition and the death of the declarer.

§ 70.122.090 Criminal conduct—penalties.

Any person who willfully conceals, cancels, defaces, obliterates, or damages the directive of another without such declarer's consent shall be guilty of a gross misdemeanor. Any person who falsifies or forges the directive of another, or willfully conceals or withholds personal knowledge of a revocation as provided in RCW 70.122.040 with the intent to cause a withholding or withdrawal of life-sustaining procedures contrary to the wishes of the declarer, and thereby, because of any such act, directly causes life-sustaining procedures to be withheld or withdrawn and death to thereby be hastened, shall be subject to prosecution for murder in the first degree as defined in RCW 9A.32.030.

§ 70.122.100 Mercy killing not authorized.

Nothing in this chapter shall be construed to condone, authorize, or approve mercy killing, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying.

§ 70.122.900 Short title.

This act shall be known and may be cited as the "Natural Death Act."

§ 70.122.905 Severability.

If any provision of this act or the application thereof to any person or circumstances is held invalid, such invalidity shall not affect other provisions or applications of the act which can be given effect without the invalid provisions or application, and to this end the provisions of this act are severable.

Wash. Rev. Code Ann. §§ 70.122.010 through 70.122.905 (June 7, 1979).

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E

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Table E1.

Provisions of Existing Durable Power of Attorney Statutes

	Virginia Model(2)	California Kansas Massachusetts	Arkansas Oklahoma Wyoming	Tennessee	Florida	North Carolina	Georgia Louisiana Oregon
Is court approval required for decisions regarding the person?	No	Yes	Yes	No	No(3)	No	No
Is registration or filing required?(1)	No	No	Yes	No	No	Yes	No
Is there a procedure for delegation of power?	No	No	Yes	No	No	Yes	No
Must durable power of attorney be specified?	Yes	Yes	Yes	Yes	Yes	Yes	No(4)
Can durable power of attorney be used to nominate conservator or guardian?	No Law	Creates Strong Presumption	No	No	No	No	No
Must accounting be given to court at specified times?	No Law	No Law	Yes	No	No	No	No
Are there restrictions as to who can serve as attorney?	No	No	No	No	Limited to certain family members	No	No

(1) South Carolina requires recording durable power of attorney in the same manner as a deed. In South Dakota it *may* be recorded.

(2) The following states have adopted durable power of attorney statutes patterned after Virginia's: Alaska, Arizona, Colorado, Delaware, Hawaii, Idaho, Indiana, Iowa, Kentucky, Maine, Michigan, Minnesota, Nebraska, New Mexico, New York, North Dakota, Maryland, Pennsylvania, South Carolina, Texas, Utah, Vermont, Washington, West Virginia, Virginia.

(3) If principal is *adjudicated* incompetent, power of attorney lapses.

(4) Power of attorney is durable unless otherwise specified.

Uniform Durable Power of Attorney Act*

§ 1. [Definition]

A durable power of attorney is a power of attorney by which a principal designates another his attorney in fact in writing and the writing contains the words "This power of attorney shall not be affected by subsequent disability or incapacity of the principal," or "This power of attorney shall become effective upon the disability or incapacity of the principal," or similar words showing the intent of the principal that the authority conferred shall be exercisable notwithstanding the principal's subsequent disability or incapacity.

§ 2. [Durable Power of Attorney Not Affected By Disability or Incapacity]

All acts done by an attorney in fact pursuant to a durable power of attorney during any period of disability or incapacity of the principal have the same effect and inure to the benefit of and bind the principal and his successors in interest as if the principal were competent and not disabled.

§ 3. [Relation of Attorney in Fact to Court-appointed Fiduciary]

(a) If, following execution of a durable power of attorney, a court of the principal's domicile appoints a conservator, guardian of the estate, or other fiduciary charged with the management of all of the principal's property or all of his property except specified exclusions, the attorney in fact is accountable to the fiduciary as well as to the principal. The fiduciary has the same power to revoke or amend the power of attorney that the principal would have had if he were not disabled or incapacitated.

(b) A principal may nominate, by a durable power of attorney, the conservator, guardian of his estate, or guardian of his person for consideration by the court if protective proceedings for the principal's person or estate are thereafter commenced. The court shall make its appointment in accordance with the principal's most recent nomination in a durable power of attorney except for good cause or disqualification.

§ 4. [Power of Attorney Not Revoked Until Notice]

(a) The death of a principal who has executed a power of attorney, durable or otherwise, does not revoke or terminate the agency as to the attorney in fact or other person, who, without actual knowledge of the death of the principal, acts in good faith under the power. Any action so taken, unless otherwise invalid or unenforceable, binds successors in interest of the principal.

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* Unif. Durable Power of Attorney Act § 1-10, 8 U.L.A. 74 (1982).

(b) The disability or incapacity of a principal who has previously executed a power of attorney that is not a durable power does not revoke or terminate the agency as to the attorney in fact or other person, who, without actual knowledge of the disability or incapacity of the principal, acts in good faith under the power. Any action so taken, unless otherwise invalid or unenforceable, binds the principal and his successors in interest.

§ 5. [Proof of Continuance of Durable and Other Powers of Attorney by Affidavit]

As to acts undertaken in good faith reliance thereon, an affidavit executed by the attorney in fact under a power of attorney, durable or otherwise, stating that he did not have at the time of exercise of the power actual knowledge of the termination of the power by revocation or of the principal's death, disability, or incapacity is conclusive proof of the nonrevocation or nontermination of the power at that time. If the exercise of the power of attorney requires execution and delivery of any instrument that is recordable, the affidavit when authenticated for record is likewise recordable. This section does not affect any provision in a power of attorney for its termination by expiration of time or occurrence of an event other than express revocation or a change in the principal's capacity.

§ 6. [Uniformity of Application and Construction]

This Act shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this Act among states enacting it.

§ 7. [Short Title]

This Act may be cited as the Uniform Durable Power of Attorney Act.

§ 8. [Severability]

If any provision of this Act or its application to any person or circumstances is held invalid, the invalidity does not affect other provisions or applications of the Act which can be given effect without the invalid provision or application, and to this end the provisions of this Act are severable.

§ 9. [Time of Taking Effect]

This Act takes effect _____.

§ 10. [Repeal]

The following acts and parts of acts are repealed:

(1)

(2)

(3)

Durable Power of Attorney Statutes, by State*

Alaska

§ 13.26.325. [Adopted the statute reprinted under Arizona, except that verb form in first sentence is altered.]

Alaska Stat.§ 13.26.325 (1973) (effective Jan. 1, 1973).

Arizona

§ 14-5501. When power of attorney not affected by disability.

Whenever a principal designates another his attorney-in-fact or agent by a power of attorney in writing and the writing contains the words "this power of attorney shall not be affected by disability of the principal," or "this power of attorney shall become effective upon the disability of the principal," or similar words showing the intent of the principal that the authority conferred shall be exercisable notwithstanding his disability, the authority of the attorney-in-fact or agent is exercisable by him as provided in the power on behalf of the principal notwithstanding later disability or incapacity of the principal at law or later uncertainty as to whether the principal is dead or alive. All acts done by the attorney-in-fact or agent pursuant to the power during any period of disability or incompetence or uncertainty as to whether the principal is dead or alive have the same effect and inure to the benefit of and bind the principal or his heirs, devisees and personal representative as if the principal were alive, competent and not disabled. If a conservator thereafter is appointed for the principal, the attorney-in-fact or agent, during the continuance of the appointment, shall account to the conservator rather than the principal. The conservator has the same power the principal would have had if he were not disabled or incompetent, to revoke, suspend or terminate all or any part of the power of attorney or agency.

Ariz. Rev. Stat. Ann. § 14-5501 (1975) (effective Jan. 1, 1974).

Arkansas

§ 58-501. Execution—Purpose—Approval.

* Statutes have been edited only where necessary to correct spelling and to standardize printing format.

(a) If a resident of this State desires to execute a power of attorney in anticipation or because of infirmity resulting from injury, old age, senility, blindness, disease, or other related or similar cause as a means of providing for the care of his or her person or property, or both, he or she shall execute the instrument in one [1] of the following three [3] methods:

(1) in the presence of and with the approval of the Judge of the Probate Court of the county of the principal's domicile, or

(2) in the presence of at least two [2] witnesses who shall attest and prove the execution by affidavit to be filed with said instrument, to be approved by the Probate Court of the county of the principal's domicile, or

(3) in the presence of a notary public who shall acknowledge the same, which instrument with the certificate of said notary public shall be filed with and approved by the Probate Court of the county of the principal's domicile.

The power is not invalidated by reason of any subsequent change in the mental or physical condition of the principal, including but not restricted to incompetency.

(b) The approval of the judge may be given only if:

(1) the principal requests approval;

(2) the attorney in fact consents to serve;

(3) the judge is satisfied, after any examination and investigation he deems appropriate, that the principal is a person covered by this Act and reasonably understands the nature and purpose of the power, and that the attorney in fact is a suitable person to carry out the obligations imposed upon him; and

(4) the provisions of this Act have been observed. Approval may be given informally in chambers or other convenient place without the necessity of service of summons or other notice and shall be endorsed upon the face of the original of the instrument.

The power remains valid until terminated as provided in this Act.

§ 58-502. Scope and applicability of the power.

(a) The power of attorney shall show or state:

(1) the fact of execution under the provisions of this Act;

(2) the time and conditions under which the power is to become effective;

(3) the extent and scope of the power conferred;

(4) who is to exercise the power; and

(5) the annual income covered by the instrument and the nature or description and estimated value of the property, if any, to be affected; and may state the conditions and circumstances under which the power terminates.

(b) The power may be restricted or it may grant complete authority to provide for the care of the principal's person and property. Except to the extent limited by the instrument creating the power or to the extent that court approval is required by the instrument, the attorney in fact without prior court approval may endorse checks and other instruments made payable to the principal; may sell, encumber, lease, or otherwise manage the principal's property; and may execute and deliver deeds, conveyances, stock and bond transfers, contracts and other instruments necessary to carry out the power.

§ 58-503. Attorney in fact—filing of power.

(a) The attorney in fact may be an individual, a corporation authorized by law to act in a fiduciary capacity, an agency of government, a Community Fund or United Fund participating agency, or the American National Red Cross.

(b) The original power of attorney shall be filed in the office of the clerk of the Probate Court of the county of the domicile of the principal and a certified copy thereof, together with the record of judicial approval, shall be recorded in the office of the recorder of each county in which real property to be affected by an exercise of the power is located.

§ 58-504. Limit of power.

A power of attorney executed under authority of this Act which grants powers concerning propery [property] or income shall be approved only if limited to (1) property having a gross value not exceeding $20,000, exclusive of homestead and, excluding the capitalized value of any annual income, or (2) an annual money income covered by the instrument not exceeding $6,000. A performance bond shall not be filed unless required by a provision of the power.

§ 58-505. Removal of attorney in fact—appointment of successor.

If the attorney in fact or any successor dies, ceases to act, refuses or is unable to serve, resigns, fails to maintain or replace a bond, or is removed for cause by a court, a successor attorney in fact may be appointed by the principal. If the principal, without having revoked the power of attorney, fails or is unable to appoint a successor within a reasonable time, a judge of the court which approved the power may appoint a successor, unless precluded from doing so by provisions of the original power of attorney. The appointment of a successor attorney in fact shall be in writing. If the appointment is by the principal, it is subject to approval by a judge of the court which approved the original power. The original and certified copies of the appointment of the successor shall be filed and recorded as required for an original power of attorney.

§ 58-506. Termination of power—filing—protection of third persons—acts done after termination.

(a) A power of attorney terminates on:

(1) written revocation by the principal;

(2) death of the principal;

(3) order of a court appointing a guardian, of the person or property or both of the principal, unless the order otherwise provides;

(4) expiration or termination as specified in the power of attorney; or

(5) a determination by a judge of the approving court that the value of the property or the amount of the annual money income covered by the instrument has so increased that this Act is no longer appropriately applicable.

(b) The original resignation of an attorney in fact, a written revocation of the power of attorney by a principal, or a certified copy of the death certificate of the principal or of the attorney in fact or of any court judgment or order terminating the power of attorney or removing the attorney in fact for cause, shall be filed promptly in the office of the clerk of the court whose judge approved the power, and certified copies shall be recorded promptly in all offices in which a certified copy of the original power of attorney is recorded. A notation of the terminating event shall be made by the clerk on the face of the original power of attorney.

(c) A person dealing with the attorney in fact is not required to inquire into the validity or adequacy of proceedings involving an approval or filing and recording of the power of attorney to determine if the principal or attorney in fact is qualified, or to determine whether the power may have been terminated if not yet shown by filing and recording under subsection (b). He is not required to inquire into the validity or propriety of any act of an attorney in fact apparently authorized by his approved power, or to assure the proper application by the attorney in fact of any money or property paid or delivered to him.

(d) The attorney in fact is liable to the principal and the principal's estate for all damage and loss the principal suffers because of the attorney's acts done after the attorney receives notice of the termination of his authority or after termination by provision of the power itself. After the power is terminated, other than by death of the principal, he may perform ministerial acts reasonably necessary to complete and conclude his duties.

§ 58-507. Liability of attorney in fact.

Unless otherwise provided in the power of attorney, an attorney in fact is bound by standards of conduct and liability applicable to other fiduciaries.

§ 58-508. Expenses—compensation for services.

An attorney in fact is entitled to reimbursement for his reasonable expenses incurred in the performance of his duties and, unless precluded by the power of attorney, to reasonable compensation for his services, payable out of the income and assets subject to the power. The amount of compensation and time of payment may be fixed in the power.

§ 58-509. Duty to account.

An attorney in fact shall account to the principal or his legal representative at times specified in the power of attorney, at any time directed by a judge of the approving court, and upon termination of the power or his authority; and he shall deliver promptly to the principal, his legal representative, or a successor attorney in fact all property held by him as attorney in fact upon termination of the power or his authority.

§ 58-510. Act limited to powers executed under it.

This Act governs only powers of attorney executed under it. It does not affect powers of attorney executed under other statutes or the common law of this State.

§ 58-511. Construction.

The provisions of this Act shall be liberally construed so as to effectuate its purposes.

Ark. Stat. Ann. §§ 58-501 to 511 (1971) (effective Feb. 12, 1965).

California

[Adopted the Uniform Durable Power of Attorney Act.]

Cal. Ann. Civ. Code §§ 2400 to 2407 (Deering 1983) (effective Sept. 16, 1981).

Colorado

§ 15-14-501. When power of attorney not affected by disability.

[Subsection (1) is identical to statute reprinted under Arizona.]

(2) An affidavit, executed by the attorney-in-fact or agent, stating that he did not have, at the time of doing an act pursuant to the power of attorney, actual knowledge of the termination of the power of attorney by death is, in the absence of fraud, conclusive proof of the nontermination of the power at that time. If the exercise of the power requires execution and delivery of any instrument which is recordable, the affidavit when authenticated for record is likewise recordable.

Colo. Rev. Stat. § 15-14-501 (Cum. Supp. 1982).

Delaware

§ 4901. Defined.

A durable power of attorney is a power of attorney by which a principal designates another his attorney-in-fact in writing, and the writing contains the words: "This power of attorney shall not be affected by subsequent disability or incapacity of the principal," or "This power of attorney shall become effective upon the disability or incapacity of the principal," or similar words showing the intent of the principal that the authority conferred shall be exercisable notwithstanding the principal's subsequent disability or incapacity.

§ 4902. Power not affected by disability.

All acts done by an attorney-in-fact pursuant to a durable power of attorney during any period of disability or incapacity of the principal have the same effect and inure to the benefit of and bind the principal, and his successors in interest, as if the principal were competent and not disabled.

§ 4903. Relation of attorney-in-fact to court-appointed fiduciary.

(a) The appointment of a guardian or other fiduciary charged with the management of the principal's property or the care of his person shall terminate all powers of attorney created pursuant to this chapter to the extent the powers held by the attorney-in-fact prior to the appointment of a guardian or other fiduciary are granted to the guardian or other fiduciary; provided, however, that the person or entity serving as attorney-in-fact pursuant to this chapter shall, upon his request and absent cause to the contrary, be appointed the guardian or other fiduciary in a proceeding under Chapter 37 or Chapter 39 of this title.

(b) After the appointment of a guardian or other fiduciary charged with the management of the pricipal's property or the care of his person, the attorney-in-fact is accountable to such guardian or other fiduciary as well as to principal as to any powers which the attorney-in-fact continues to hold. A guardian or other fiduciary shall only have such powers to revoke or amend the powers of the attorney-in-fact as shall be given to such guardian or other fiduciary by the court.

§ 4904. Notice required for revocation.

(a) The death of a principal who has executed a written power of attorney, durable or otherwise, does not revoke nor terminate the agency as to the attorney-in-fact, or other person who, without actual knowledge of the death of the principal, acts in good faith under the power. Any action so taken, unless otherwise invalid or unenforceable, binds the successors in interest of the principal.

(b) The disability or incapacity of a principal who has previously executed a written power of attorney that is not a

durable power does not revoke nor terminate the agency as to the attorney-in-fact, or other person who, without actual knowledge of the disability or incapacity of the principal, acts in good faith under the power. Any action so taken, unless otherwise invalid or unenforceable, binds the principal and his successors in interest.

§ 4905. Effect of affidavit.

As to acts undertaken in good faith reliance thereon, an affidavit executed by the attorney-in-fact under a power of attorney, durable or otherwise, stating that he did not have at the time of exercise of the power actual knowledge of the termination of the power by revocation or of the principal's death, disability or incapacity is conclusive proof of the nonrevocation or nontermination of the power at that time. If the exercise of the power of attorney requires execution and delivery of any instrument that is recordable, the affidavit when authenticated for record is likewise recordable. This section does not affect any provision in a power of attorney for its termination by expiration of time, the occurrence of an event other than an expressed revocation or a change in the principal's capacity.

Del. Code Ann. tit. 12, §§ 4901 to 4905 (Cum. Supp. 1982) (effective June 21, 1982).

Florida

§ 709.08. Durable family power of attorney.

(1) A principal may create a durable family power of attorney designating his spouse, parent, child, whether natural or adopted, brother, or sister his attorney in fact by executing a power of attorney. Such power of attorney shall be in writing, shall state the relationship of the parties, and shall include the words, "This durable family power of attorney shall not be affected by disability of the principal except as provided by statute" or similar words clearly showing the intent of the principal that the power conferred on the attorney in fact shall be exercisable from the date specified in the instrument, notwithstanding a later disability or incapacity of the principal, unless otherwise provided by statute. All acts done by the attorney in fact pursuant to the power conferred during any period of disability or incompetence shall have the same effect, and inure to the benefit of and bind the principal or his heirs, devisees, and personal representatives, as if the principal were competent and not disabled.

(2) The durable family power of attorney shall be nondelegable and shall be valid until such time as the donor shall die, revoke the power, or be adjudged incompetent. At any

time, a petition to determine competency of the donor or a petition to appoint a guardian for the donor has been filed, the durable family power of attorney shall be temporarily suspended. Notice of the pending petition shall be given to all known donees of the power. The power shall remain suspended until the petition is dismissed, withdrawn, or the donor adjudged competent, at which time the power shall be automatically reinstated and any exercise of the power shall be valid. If the donor is adjudged incompetent, the power shall be automatically revoked.

(3) Property subject to the durable family power of attorney shall include all real and personal property owned by the donor, the donor's interest in all property held in joint tenancy, the donor's interest in all nonhomestead property held in tenancy by the entirety, and all property over which the donor holds a power of appointment. Nothing in this section shall permit the donee of a durable family power of attorney, when the donor is married, to mortgage or convey homestead property without the joinder of the spouse or the spouse's legal guardian, but the joinder may be accomplished through the exercise of a power of attorney.

(4) Whenever an emergency shall arise between the time a petition is filed and an adjudication is made regarding the competency of the donor, the donee of the durable family power of attorney may petition the court for permission to exercise the power. The petition shall specify the emergency, the property involved, and the proposed action of the donee. No exercise of the power by the donee during this time period shall be valid without the permission of the court.

Fla. Stat. § 709.08 (Cum. Pocket Part 1983) (effective Jan. 1, 1975; amended to add brothers and sisters as permissible family power of attorney June 17, 1977).

Georgia

§ 10-6-36. Effect of incompetency of principal on power of attorney.

A written power of attorney, unless expressly providing otherwise, shall not be terminated by the incompetency of the principal. The power to act as an attorney in fact for a principal who subsequently becomes incompetent shall remain in force until such time as a guardian or receiver shall be appointed for the principal or until some other judicial proceeding shall terminate the power.

Ga. Code Ann. § 10-6-36 (1982) (enacted 1973).

Hawaii

[Adopted the statute reprinted under Arizona.]
Hawaii Rev. Stat. § 560:5-501 (Supp. 1981) (enacted 1976).

Idaho

[Adopted the statute reprinted under Arizona.]
Idaho Code §§ 15-5-501 to 502 (1982).

Indiana

[Adopted the statute reprinted under Arizona, except that "guardian" is substituted for "conservator."]
Ind. Code § 30-2-1.5-1 (1981) (enacted 1976).

Iowa

§ 633.705. When power of attorney not affected by disability.

Whenever a principal designates another his attorney in fact or agent by a power of attorney in writing and the writing contains the words "This power of attorney shall not be affected by disability of the principal", or "This power of attorney shall become effective upon the disability of the principal", or similar words showing the intent of the principal that the authority conferred shall be exercisable notwithstanding his disability, the authority of the attorney in fact or agent is exercisable by him as provided in the power on behalf of the principal notwithstanding later disability or incapacity of the principal or later uncertainty as to whether the principal is dead or alive. All acts done by the attorney in fact or agent pursuant to the power during any period of disability or incompetence or uncertainty as to whether the principal is dead or alive have the same effect and inure to the benefit of and bind the principal and his heirs, devisees, and personal representatives as if the principal were alive, competent and not disabled. If a conservator thereafter is appointed for the principal, the attorney in fact or agent, during the continuance of the appointment, shall account to the conservator rather than the principal, and the conservator shall have the power to

revoke the power of attorney on behalf of the principal.
Iowa Code Ann. § 633.705 (West 1983) (effective 1975).

Kansas

[Adopted the Uniform Durable Power of Attorney Act, with minor variations in wording.]
Kan. Stat. Ann. §§ 58-610 to 617 (Cum. Supp. 1981) (enacted April 4, 1980).

Kentucky

§ 386.093. When power of attorney not affected by disability.

When a principal designates another his attorney in fact or agent by a power of attorney in writing and the writing contains the words "This power of attorney shall not be affected by the disability of the principal," or "This power of attorney shall become effective upon the disability of the principal," or similar words showing the intent of the principal that the authority conferred shall be exercisable notwithstanding his disability, then the authority of the attorney in fact or agent is exercisable by him as provided in the power on behalf of the principal notwithstanding later disability or incapacity of the principal at law or later uncertainty as to whether the principal is dead or alive. All acts done by the attorney in fact or agent, pursuant to the power during any period of disability or incompetence or uncertainty as to whether the principal is dead or alive have the same effect and inure to the benefit of and bind the principal or his heirs, devisees and personal representative as if the principal were alive, competent and not disabled. If a fiduciary is thereafter appointed by the court for the principal the power of the attorney in fact shall thereupon terminate and he shall account to the court's appointed fiduciary.

Ken. Rev. Stat. Ann. § 386.093 (Baldwin 1982) (effective June 16, 1972).

Louisiana

All powers of attorney are durable unless they provide to the contrary. *See* Succession of McCrocklin, 242 La. 404, 137 So.2d 74 (1962).

Maine

[Adopted the statute reprinted under Arizona.]

Me. Rev. Stat. Ann. Tit. 18-A, § 5-501 (1964) (effective Jan. 1, 1981).

Maryland

§ 13-601. When power of attorney not affected by disability.

(a) Form and extent of power.—If a principal designates his attorney in fact or agent by a power of attorney in writing and the writing contains the words

(1) "This power of attorney shall not be affected by disability of the principal," or

(2) "This power of attorney becomes effective upon the disability of the principal," or

(3) Similar words showing the intent of the principal that the authority conferred shall be exercisable notwithstanding his disability, the authority of the attorney in fact or agent is exercisable by him notwithstanding the later disability of the principal or uncertainty whether the principal is dead or alive.

(b) Effect of acts performed for an incapacitated principal.—Any act done by the attorney in fact or agent pursuant to the power during any period of disability or incompetence or uncertainty as to whether the principal is dead or alive has the same effect and inures to the benefit of and binds the principal as if the principal were alive, competent, and not disabled.

(c) Appointment of guardian.—If a guardian is appointed for the principal, the attorney in fact or agent shall account to the guardian rather than the principal. The guardian has the same power the principal would have but for his disability or incompetence to revoke, suspend, or terminate all or any part of the power of attorney or agency.

Md. Est. & Trusts Code Ann. § 13-601 (1974) (enacted 1974).

Massachusetts

[Adopted the Uniform Durable Power of Attorney Act.]

Mass. Gen. Laws Ann. ch. 201B, §§ 1 to 7 (West 1981) (effective June 22, 1981).

Michigan

[Adopted the statute reprinted under Arizona, with minor variations in wording.]

Mich. Stat. Ann. § 27.5495 (Callaghan 1980).

Minnesota

[Adopted the statute reprinted under Arizona, with minor variations in wording.]

Minn. Stat. § 524.5-501 (West 1976) (effective Jan. 1, 1976).

Montana

[Adopted the statute reprinted under Arizona.]

Mont. Code Ann. §§ 75-5-501 to 502 (1981).

Nebraska

[Adopted the statute reprinted under Arizona.]

Neb. Rev. Stat. § 30-2662 (1979) (enacted 1974).

New Jersey

46:2B-8. Power of attorney unaffected by disability of principal according to its terms; accountability to guardian; disability defined

[Subsection (a) is identical to statute reprinted under Arizona.]

(b) A principal shall be under a disability if he is unable to manage his property and affairs effectively for reasons such as mental illness, mental deficiency, physical illness or disability, advanced age, chronic use of drugs, chronic intoxication, confinement, detention by a foreign power, or disappearance.

N.J. Stat. Ann §§ 46:2B-8 (West Cum. Supp. 1982-1983) (effective Jan. 1, 1972).

New Mexico

[Adopted the statute reprinted under Arizona, with minor variations in wording.]

N.M. Stat. Ann. § 45-5-501 (1978) (enacted 1975).

New York

§ 5-1601. Powers of attorney which survive disability or incompetence.

(1) The subsequent disability or incompetence of a principal shall not revoke or terminate the authority of an attorney-in-fact who acts under a power of attorney in a writing executed by such principal which contains the words "This power of attorney shall not be affected by the subsequent disability or incompetence of the principal," or words of similar import showing the intent of such principal that the authority conferred shall be exercisable notwithstanding his subsequent disability or incompetence.

(2) All acts done by an attorney-in-fact pursuant to a power granted pursuant to subdivision one of this section during any period of disability or incompetence shall have the same effect and inure to the benefit of and bind a principal and his distributees, devisees, legatees and personal representatives as if such principal were competent and not disabled. If a committee or conservator thereafter is appointed for such principal, such attorney-in-fact, during the continuance of the appointment, shall account to the committee or conservator rather than to such principal. The committee or conservator shall have the same power such principal would have had if he were not disabled or incompetent to revoke, suspend or terminate all or any part of such power of attorney.

N.Y. Gen. Oblig. Law § 5-1601 (McKinney 1978) (effective June 10, 1975).

North Carolina

§ 47-115.1. Appintment of attorney-in-fact which may be continued in effect notwithstanding incapacity or mental incompetence of the principal therein.

(a) Any person 18 years of age or more and mentally incompetent may as principal execute a power of attorney pursuant to the provisions of this section which shall continue in effect until revoked as hereinafter provided, notwithstand-

ing any incapacity or mental incompetence of such principal which occurs after the date of the execution and acknowledgement of the power of attorney.

(b) The power of attorney shall be in writing, signed by the principal under seal, acknowledged by the principal before an officer authorized to take the acknowledgment of deeds whose authority is recognized under the law of North Carolina in effect at the time of such acknowledgment, and delivered to the attorney-in-fact.

(c) The power of attorney shall contain a statement that it is executed pursuant to the provisions of this section, or shall contain such other language as shall clearly indicate the intention that the power of attorney shall continue in effect notwithstanding the incapacity or incompetence of the principal.

(d) No power of attorney executed pursuant to the provisions of this section shall be valid but from the time of registration thereof in the office of the register of deeds of that county in this State designated in the power of attorney, or if no place of registration is designated, in the office of the register of deeds of the county in which the principal has his legal residence at the time of such registration or, if the principal has no legal residence in this State at the time of registration or the attorney-in-fact is uncertain as to the principal's residence in this State, in some county in the State in which the principal owns property or the county in which one or more of the attorneys-in-fact reside. A power of attorney executed pursuant to the provisions of this section shall be valid from the time of registration thereof even though the time of such registration is subsequent to the mental incapacity or incompetence of the principal. Within 30 days after the registration of the power of attorney as above provided, the attorney-in-fact shall file with the clerk of the superior court in the county of such registration a copy of the power of attorney, but failure to file with the clerk shall not affect validity of the instrument.

(e) Every power of attorney executed pursuant to the provisions of this section shall be revoked by:

(1) The death of the principal; or

(2) The appointment of a guardian or trustee of the property in this State of the principal, and the registration of a certified copy of such appointment in the office of the register of deeds where the power of attorney has been registered; or

(3) Registration in the office of the register of deeds where the power of attorney has been registered of an instrument of revocation executed and acknowledged by the principal while he is not incapacitated or mentally incompetent, or by the registration in such office of an instrument of revocation executed by any person or corporation who is given

such power of revocation in the power of attorney, with proof of service thereof in either case on the attorney-in-fact in the manner prescribed for service of summons in civil actions.

(f) Any person dealing in good faith with an attorney-in-fact acting under a power of attorney executed and then in effect under this section shall be protected to the full extent of the powers conferred upon such attorney-in-fact, and no person so dealing with such attorney-in-fact shall be responsible for the misapplication of any money or other property paid or transferred to such attorney-in-fact.

(g) Every attorney-in-fact acting under a power of attorney in effect under this section shall keep full and accurate records of all transactions in which he acts as agent of the principal and of all property of the principal in his hands and the disposition thereof.

(h) If the power of attorney provides for rendering inventories and accounts, such provisions shall govern. Otherwise, the attorney-in-fact shall file in the office of the clerk of the superior court of the county in which the power of attorney is registered, inventories of the property of the principal in his hands and annual and final accounts of the receipt and disposition of property of the principal and of other transactions in behalf of the principal. The power of the clerk to enforce the filing and his duties in respect to audit and recording of such accounts shall be the same as those in respect to the accounts of administrators, but the fees and charges of the clerk shall be computed or fixed only with relation to property of the principal required to be shown in the accounts and inventories. The fees and charges of the clerk shall be paid by the attorney-in-fact out of the principal's money or other property and allowed in his accounts. If the powers of an attorney-in-fact shall terminate for any reason whatever, he, or his executors or administrators, shall have the right to have a judicial settlement of a final account by any procedure available to executors, administrators or guardians.

(i) A power of attorney executed under this section may contain any provisions, not unlawful, relating to the appointment, resignation, removal and substitution of an attorney-in-fact, and to the rights, powers, duties and responsibilities of the attorney-in-fact.

(j) If all attorneys-in-fact named in the instrument or substituted shall die, or cease to exist, or shall become incapable of acting, and all methods for substitution provided in the instrument have been exhausted, such power of attorney shall cease to be effective. Any substitution by a person authorized to make it shall be in writing signed and acknowledged by such person. Notice of every other substitution shall be in writing signed and acknowledged by the person substituted. No substitution or notice shall be effective until it has been

recorded in the office of the register of deeds of the county in which the power of attorney has been recorded.

(k) In the event that any power of attorney executed pursuant to the provisions of this section does not contain the amount of commissions that the attorney-in-fact is entitled to receive or the way such commissions are to be determined, and the principal should thereafter become incompetent, the commissions such attorney-in-fact shall receive shall be fixed in the discretion of the clerk of superior court pursuant to the provisions of G.S. 28-170.

N.C. Gen. Stat. § 47-115.1 (Cum. Supp. 1981).

North Dakota

[Adopted the statute reprinted under Arizona.]

N.D. Cent. Code § 30.1-30-01 (1976) (enacted 1973).

Ohio

§ 1337.09. Written power of attorney regarding disability, incapacity, or incompetency of principal; effect.

Whenever a principal designates another his attorney in fact by a power of attorney in writing and the writing contains the words "this power of attorney shall not be affected by disability of the principal," or words of similar import, the authority of the attorney in fact is exercisable by him as provided in the written instrument notwithstanding the later disability, incapacity, or adjudged incompetency of the principal. All acts done by the attorney in fact pursuant to the written instrument during any period of disability, incapacity, or adjudged incompetency of the principal shall have the same effect and inure to the benefit of and bind the principal or his heirs, devisees, and personal representatives as if the principal were competent and not disabled or incapacitated. If a guardian thereafter is appointed for the principal, the attorney in fact, during the continuance of the appointment, shall account to the guardian rather than the principal. The guardian has the same power the principal would have had if not incompetent, to revoke all or any part of the power and the authority of the attorney in fact.

Ohio Rev. Code Ann. § 1337.09 (Page 1979) (effective July 12, 1976).

Oklahoma

§ 1051. Execution of power of attorney in anticipation of or because of infirmity—approval.

(a) If a person within this state, otherwise having capacity to contract, desires to execute a power of attorney in anticipation of or because of infirmity resulting from injury, old age, senility, blindness, disease or other related or similar cause as a means of providing for the care of his person or property, or both, he shall sign the instrument in the presence of and with the approval of the county judge of the county in which the person executing the instrument is a resident.

(b) The approval of the judge may be given only if (1) the principal requests approval, (2) the attorney in fact consents to serve, (3) the judge is satisfied, after any examination and investigation he deems appropriate, that the principal is a person covered by this act and reasonably understands the nature and purpose of the power, and that the attorney in fact is a suitable person to carry out the obligations imposed upon him, and (4) the provisions of this act have been observed. Approval may be given informally in chambers or other convenient place without the necessity of service of summons or other notice and shall be endorsed upon the face of the original of the instrument. The power is not invalidated by reason of any subsequent change in the mental or physical condition of the principal, including but not restricted to incompetency. The power remains valid until terminated as specified in Section 6.

§ 1052. Contents—powers granted.

(a) The power of attorney shall show or state (1) the fact of execution under the provisions of this act, (2) the time and the conditions under which the power is to become effective, (3) the extent and scope of the power conferred, (4) who is to exercise the power, (5) the annual income covered by the instrument and the nature or description and estimated value of the property, if any, to be affected; and may state the conditions and circumstances under which the power terminates.

(b) The power may be restricted or it may grant complete authority to provide for the care of the principal's person and property. Except to the extent limited by the instrument creating the power or to the extent that court approval is required by the instrument, the attorney in fact, without prior court approval, may endorse checks and other instruments made payable to the principal; may sell, encumber, lease, or otherwise manage the principal's property; and may execute and deliver deeds, conveyances, contracts, and other instruments necessary to carry out the power.

§ 1053. Attorney in fact—filing of power of attorney.

(a) The attorney in fact may be an individual, a corporation authorized by law to act in a fiduciary capacity, an agency of government, a Community Fund or United Fund participating agency, the American National Red Cross, or any similar charitable or benevolent agency found by the judge to be suitable thus to act.

(b) The original power of attorney shall be filed in the office of the clerk of the court whose judge approves the power. A certified copy shall be filed or recorded as may be appropriate in the office of the county clerk of the county of the principal's residence and of each county in which real property to be affected by an exercise of the power is located.

§ 1055. Successor attorney in fact.

If the attorney in fact, or any successor, dies, ceases to act, refuses or is unable to serve, resigns, fails to maintain or replace a bond, or is removed for cause by a court, a successor attorney in fact may be appointed by the principal. If the principal, without having revoked the power of attorney, fails or is unable to appoint a successor within a reasonable time, a judge of the court which approved the power may appoint a successor, unless precluded from doing so by the provisions of the original power of attorney. The appointment of a successor attorney in fact shall be in writing. If the appointment is by the principal, it is subject to approval by a judge of the court which approved the original power. The original and certified copies of the appointment of the successor shall be filed or recorded as required for an original power of attorney.

§ 1056. Termination of power—persons dealing with attorney in fact—acts after termination.

(a) A power of attorney terminates on (1) written revocation by the principal, (2) death of the principal, (3) order of a court appointing a guardian of person or property, or both, of the principal, unless the order otherwise provides, or (4) expiration or termination as specified in the power of attorney.

(b) The original resignation of an attorney in fact or written revocation of the power of attorney by a principal, a certified copy of the death certificate of the principal or of the attorney in fact or of any court judgment or order terminating the power of attorney or removing the attorney in fact for cause shall be filed promptly in the office of the clerk of the court whose judge approved the power; and certified copies shall be filed or recorded promptly in all offices in which a certified copy of the original power of attorney is filed or recorded. A notation of the terminating event shall be made by the clerk on the face of the original power of attorney.

(c) A person dealing with the attorney in fact is not required to inquire into the validity or adequacy of proceedings involving an approval, filing, or recording of the power of attorney, to determine if the principal or attorney in fact is

qualified or to determine whether the power may have been terminated if not yet shown by filing or recordation provided for in subsection (b). He is not required to inquire into the validity or propriety of any act of an attorney in fact apparently authorized by his approved power, or to assure the proper application by the attorney in fact of any money or property paid or delivered to him.

(d) The attorney in fact is liable to the principal and the principal's estate for all damage and loss the principal suffers because of the attorney's acts done after the attorney receives notice of the termination of his power or after termination by provision of the power itself. After his power is terminated, other than by death of the principal, he may perform such ministerial acts as may be reasonably necessary to complete and conclude his duties.

§ 1057. Standards of conduct and liability.

An attorney in fact is bound by standards of conduct and liability applicable to other fiduciaries.

§ 1058. Expenses—compensation.

An attorney in fact is entitled to reimbursement for his reasonable expenses incurred in the performance of his duties and, unless precluded by the power of attorney, to reasonable compensation for his services, payable out of the income and assets subject to the power. The amount of compensation and time of payment may be fixed in the power.

§ 1059. Accounting.

An attorney in fact shall account to the principal or his legal representative at times specified in the power of attorney and at any time directed by a judge of the approving court and upon termination of the power, and shall promptly deliver to the principal or his legal representative all property held by the attorney in fact upon termination of the power.

§ 1060. Other powers of attorney unaffected.

This act governs only powers of attorney executed under it. It does not affect powers of attorney executed under other statutes or the common law of this state.

§ 1061. Liberal construction.

The provisions of this act shall be liberally construed so as to effectuate its purposes.

§ 1062. Effect of acts of attorney—termination of power.

All powers of attorney other than those executed in anticipation of physical or mental infirmities shall be irrevocable if any such infirmity occurs only if the principal so states in the writing by which the power is granted. All acts done by the attorney in fact or agent pursuant to the power during any period of infirmity shall bind the principal. Any power of attorney so granted shall terminate on the written revocation by the principal, death of the principal, appointment of a

guardian of the person and/or property of the principal, unless the order of appointment otherwise provides, or upon its expiration or termination according to its terms.

Okla. Stat. Ann. tit. 58, §§ 1051 to 1062 (West 1983) (effective June 16, 1965).

Oregon

§ 126.407. When power of attorney not affected during period of disability; accounting to conservator.

(1) When a principal designates another his attorney-in-fact or agent by a power of attorney in writing and the writing does not contain words which otherwise limit the period of time of its effectiveness, the powers of the attorney-in-fact or agent shall be exercisable by him on behalf of the principal notwithstanding the later disability or incompetence of the principal at law.

(2) All acts done by the attorney-in-fact or agent under the power of attorney during any period of disability or incompetence of the principal at law shall have the same effect and shall inure to the benefit of and bind the principal as though the principal were not disabled or incompetent.

(3) If a conservator is appointed thereafter for the principal, the attorney-in-fact or agent, during the continuation of that appointment, shall account to the conservator rather than to the principal. The conservator has the same power that the principal would have, but for his disability or incompetence, to revoke, suspend or terminate all or any part of the power of attorney or agency.

Ore. Rev. Stat. § 126.407 (1981) (enacted 1973).

Pennsylvania

§ 5601. When power of attorney not affected by disability.

Whenever a principal appoints another his attorney in fact or agent by a power of attorney in writing and the writing contains the words "This power of attorney shall not be affected by disability of the principal," or words showing the intent of the principal that the authority conferred shall be exercisable notwithstanding his disability, the authority of the attorney in fact or agent shall be exercisable by him as provided in the power on behalf of the principal notwithstanding later disability or incapacity of the principal at law or later uncertainty as to whether the principal is dead or alive. All

acts done by the attorney in fact or agent pursuant to the power during any period of disability or incompetence or uncertainty as to whether the principal is dead or alive shall have the same effect and inure to tbe benefit of and bind the principal and his heirs, legatees, devisees and personal representative as if the principal were alive, competent and not disabled. If a guardian thereafter is appointed for the estate of the principal, the attorney in fact or agent, during the continuance of the appointment, shall account to the guardian rather than the principal. The guardian shall have the same power the principal would have had if he were not disabled or the principal would have had if he had not been adjudicated incompetent or had not created the power of attorney or agency. The guardian may either permit the attorney in fact to continue to act or revoke the power of attorney.

20 Pa. Cons. Stat. Ann. § 5601 (Purdon 1976) (effective Dec. 10, 1974).

South Carolina

§ 32-13-10. Power of attorney not to be terminated by physical disability or mental incompetence of principal.

Whenever a principal designates another his attorney in fact by a power of attorney in writing and the writing contains the words "This power of attorney shall not be affected by physical disability or mental incompetence of the principal which renders the principal incapable of managing his own estate" showing the intent of the principal that the authority conferred shall be exercisable notwithstanding his physical disability or mental incompetence, the authority of the attorney in fact is exercisable by him as provided in the power on behalf of the principal notwithstanding later disability or mental incompetence of the principal. All acts done by the attorney in fact pursuant to the power during any period of disability or mental incompetence shall have the same effect and inure to the benefit of and bind the principal or his heirs, devisees, legatees and personal representative as if the principal were mentally competent and not disabled. The attorney in fact shall have a fiduciary relationship with the principal and shall be accountable and responsible as a fiduciary. The appointment of a power of attorney under this section shall not prevent a person or his representative from applying to the court and having a committee appointed after which the power of attorney shall become inoperative. A power of attorney executed under the provisions of this section shall be executed and attested with the same formality and with the same requirements as to witnesses as a will. In addition, the

instrument shall be probated and recorded in the same manner as a deed. Unless the instrument provides otherwise, the probate judge may, in his discretion, and at any time after the onset of mental disability, on motion of any interested party or his own motion, require that an inventory of all deposits, choses in action and personal property be filed with the court and a surety bond be posted by the attorney in fact in such manner and amount that would be applicable to a decedent's estate.

S.C. Code Ann. § 32-13-10 (Law Co-op. Cum. Supp. 1982) (effective Feb. 2, 1979).

South Dakota

§ 59-7-2.1. Continuing authority of agent notwithstanding disability of principal when intent shown.

Notwithstanding § 59-7-2, when a principal designates another as his attorney in fact or agent by a written power of attorney which contains the words "This power of attorney shall not be affected by disability of the principal," or "This power of attorney shall become effective upon the disability of the principal," or similar words showing the intent of the principal that the authority conferred is exercisable notwithstanding his disability, the authority of the attorney in fact or agent is exercisable by him as provided in the power on behalf of the principal notwithstanding any later disability or incapacity of the principal or later uncertainty as to whether or not the principal is dead or alive.

§ 59-7.2.2. Recording of continuing power of attorney—force and effect—duration.

Such power of attorney may be recorded with a register of deeds specified in the power of attorney, and a certified copy thereof shall have the same force and effect as the signed original. It shall be effective for the purposes granted during the lifetime of the principal, unless revoked by a revocation recorded in the office of the register of deeds where the power of attorney was originally recorded.

§ 59-7-2.3. Binding effect of agent's acts under continuing power.

All acts done by an attorney in fact or agent pursuant to the power during any period of disability or incompetence or uncertainty as to whether the principal is dead or alive have the same effect and inure to the benefit of and bind the principal or his heirs, devisees, administrators, executors and personal representatives, as if the principal were alive, competent and not disabled.

§ 59-7-2.4. Guardian appointed—accountability of agent to guardian during continuance of power—powers of guardian.

If a guardian of an estate is appointed for the principal, the attorney in fact or agent, during the continuance of the appointment, shall account to the guardian rather than the principal. A guardian has the same power his principal would have had if he were not disabled or incompetent, to revoke, suspend or terminate all or any part of a power of attorney or agency.

S.D. Codified Laws Ann. §§ 59-7-2.1 to 59-7-2.4 (1978) (enacted 1977).

Tennessee

§ 66-5-105. Effect of mental or physical debility on power of attorney.

Any power of attorney, in effect on May 4, 1977 or created thereafter, granted by a person who is sui juris at the time will remain in full force and effect and will not be revoked by operation of law if such principal granting the power of attorney expressly provides therein that mental or physical debility shall not revoke said power.

Tenn. Code Ann. § 66-5-105 (1982) (enacted 1977).

Texas

§ 36A. When power of attorney not terminated by disability.

When a principal designates another his attorney in fact or agent by power of attorney in writing and the writing contains the words "this power of attorney shall not terminate on disability of the principal" or similar words showing the intent of the principal that the power shall not terminate on his disability, then the powers of the attorney in fact or agent shall be exercisable by him on behalf of the principal notwithstanding later disability or incompetence of the principal. All acts done by the attorney in fact or agent, pursuant to the power, during any period of disability or incompetence of the principal, shall have the same effect and shall inure to the benefit of and bind the principal as if the principal were not disabled or incompetent. If a guardian shall thereafter be appointed for the principal, the powers of the attorney in fact or agent shall terminate upon the qualification of the guardian, and the attorney in fact or agent shall deliver to the guardian all assets of the estate of the ward in his possession and shall account to

the guardian as he would to his principal had the principal himself terminated his powers.

Tex. Rev. Civ. Stat. Ann. art. 36A (Vernon 1980) (effective Jan. 1, 1972).

Utah

[Adopted the statute reprinted under Arizona.]

Utah Code Ann. § 75-5-501 (1978) (enacted 1975).

Vermont

[Adopted the statute reprinted under Arizona, except that "guardian" is substituted for "conservator."]

Vt. Stat. Ann. tit. 14, § 3051 (1982) (enacted 1975).

Virginia

§ 11-9.1. When power of attorney, etc., not terminated by principal's disability.

Whenever any power of attorney or other writing, in which any principal shall vest any power or authority in an attorney in fact or other agent, shall contain the words "This power of attorney (or his authority) shall not terminate on disability of the principal" or other words showing hte intent of the principal that such power or authority shall not terminate upon his disabiity, then all power and authority vested in the attorney in fact or agent by the power of attorney or other writing shall continue and be exercisable by the attorney in fact or agent on behalf of the principal notwithstanding any subsequent disability, incompetence, or incapacity of the principal at law; and all acts done by the attorney in fact or agent, pursuant to such power or authority, during the period of any such disability, incompetence or incapacity, shall have in all respects the same effect and shall inure to the benefit of, and bind the principal as fully as if the principal were not subject to such disability, incompetence or incapacity. If any guardian or committee shall thereafter be appointed for the principal, the attorney in fact or agent shall, during the continuance of such appointment, account to such guardian or committee as he would otherwise be obligated to account to the principal; and such guardian or committee shall have the

same right and power, which the principal would have in the absence of such disability, incompetence or incapacity, to revoke, suspend or terminate all or any part of the power and authority of the attorney in fact or agent.

§ 11-9.2. Powers of attorney not revoked, prior to their termination date, until actual notice of death or disability.

(a) No agency created by a power of attorney in writing given by a principal shall be revoked or terminated by the death or disability of the principal as to the agent or other person who, without actual knowledge or actual notice of the death of the principal, has acted or acts, in good faith, under or in reliance on such power of attorney or agency, and any action so taken, unless otherwise invalid or unenforceable, shall be binding on the principal or his heirs, devisees, legatees or personal representatives of the principal.

(b) An affidavit, executed by the attorney in fact or agent, setting forth that he has not, or had not, at the time of doing any act pursuant to the power of attorney, received actual knowledge or actual notice of the revocation or termination of the power of attorney, by death, disability or otherwise, or notice of any facts indicating the same, shall, in the absence of fraud, be connclusive proof of the nonrevocation or nontermination of the power at such time. If the exercise of the power requires execution and delivery of any instrument which is recordable under the laws of this State, such affidavit when authenticated for record in the manner prescribed by law shall likewise be recordable.

(c) This section shall not be construed so as to alter or affect any provision for revocation or termination contained in such power of attorney.

Va. Code §§ 11-9.1 through 11-9.2 (1978) (enacted 1954).

Washington

[Adopted the statute reprinted under Arizona, except that "guardian" is substituted for "conservator."]

Wash. Rev. Code § 11.94.010 (1982) (effective Oct. 1, 1974).

West Virginia

§ 27-11-6. Survival of powers of attorney following disability or incompetence.

(a) The subsequent disability or incompetence of a principal shall not revoke or terminate the authority of an attorney-

in-fact who acts under a power of attorney in a writing executed by such principal prior to such disability or incompetence if such writing contains the words "This power of attorney shall not be affected or terminated by the subsequent disability or incompetence of the principal," or words of similar import clearly showing the intent of such principal that the authority conferred in such writing shall be exercisable notwithstanding the subsequent disability or incompetence of such principal.

(b) All acts done by an attorney-in-fact pursuant to a power granted pursuant to subsection (a) of this section during any period of disability or incompetence shall have the same effect and inure to the benefit of and bind a principal and his distributees, devisees, legatees and personal representatives as if such principal were competent and not disabled.

(c) The power and authority granted in this section to an attorney-in-fact or other agent is terminated upon the appointment of a committee or conservator for the principal under other provisions of this Code.

(d) This section shall not be construed so as to alter or affect any provision for revocation or termination contained in any written power of attorney.

W.Va. Code § 27-11-6 (1982) (enacted 1980).

Wisconsin

[Adopted the Uniform Durable Power of Attorney Act.]

Wis. Stat. Ann. § 243.07 (West 1982) (effective May 1, 1982).

Wyoming

§ 34-9-101. Execution of instrument; approval of judge.

(a) Instrument to be signed in presence of judge; subsequent change in condition of principal.

If a resident of or person within this state desires to execute a power of attorney in anticipation or because of infirmity resulting from injury, old age, senility, blindness, disease, or other related or similar cause as a means of providing for the care of his person or property, or both, he shall sign the instrument in the presence of and with the approval of a judge of the district court of the district in which the power is executed. The power is not invalidated by reason of any subsequent change in the mental or physical condition of the principal, including but not restricted to incompetency.

(b) Approval of judge.

The approval of the judge may be given only if:

(i) The principal requests approval;

(ii) The attorney-in-fact consents to serve;

(iii) The judge is satisfied, after any examination and investigation he deems appropriate, that the principal is a person covered by this act [§§ 34-9-101 to 34-9-110] and reasonably understands the nature and purpose of the power, and that the attorney-in-fact is a suitable person to carry out the obligations imposed upon him; and

(iv) The provisions of this act have been observed.

(c) Endorsement of approval, etc.

Approval may be given informally in chambers or other convenient place without the necessity of service of summons or other notice and shall be endorsed upon the face of the original of the instrument. The power remains valid until terminated as provided in this act.

§ 34-9-102. Contents of instrument; limitations on power; authority of attorney.

(a) Contents.

The power of attorney shall show or state:

(i) The fact of execution under the provisions of this act;

(ii) The time and the conditions under which the power is to become effective;

(iii) The extent and scope of the power conferred;

(iv) Who is to exercise the power; and

(v) The annual income covered by the instrument and the nature or description and estimated value of the property, if any, to be affected; and may state the conditions and circumstances under which the power terminates.

(b) Limitations on power; authority of attorney.

The power may be restricted or it may grant complete authority to provide for the care of the principal's person and property. Except to the extent limited by the instrument creating the power or to the extent that court approval is required by the instrument, the attorney-in-fact without prior court approval may endorse checks and other instruments made payable to the principal; may sell, encumber, lease, or otherwise manage the principal's property; and may execute and deliver deeds, conveyances, stock and bond transfers, contracts, and other instruments necessary to carry out the power.

§ 34-9-103. Who may be attorney-in-fact; filing; filing fees.

(a) Who may be attorney-in-fact.

The attorney-in-fact may be an individual, a corporation authorized by law to act in a fiduciary capacity, an agency of

government, a community fund or united fund participant agency, or the American National Red Cross.

(b) Filing, copies.

The original power of attorney shall be filed in the office of the clerk of the court whose judge approves the power. A certified copy shall be filed or recorded in the office of the county clerk of the county of the principal's residence and of each county in which real property to be affected by an exercise of the power is located.

(c) Filing fees.

The clerk of court shall collect a filing fee of five dollars ($5.00) at the time of the filing of a power of attorney if the estimated gross value of the property as set forth in the power of attorney exceeds five thousand dollars ($5,000.00) or if the annual money income exceeds one thousand dollars ($1,000.00). If the annual money income is less than one thousand dollars ($1,000.00) and the gross value of the property is less than five thousand dollars ($5,000.00), then no filing fee should be collected. The clerk of court shall record and index all powers of attorney in the same manner as papers relating to estates of incompetents are recorded and indexed.

§ 34-9-104. Limitation on value of property or income.

(a) A power of attorney executed under authority of this act [§§ 34-9-101 to 34-9-110] which grants powers concerning property or income shall be approved only if limited to:

(i) Property having a gross value not exceeding fifty thousand dollars ($50,000.00), excluding the capitalized value of any annual income; or

(ii) An annual money income covered by the instrument not exceeding three thousand dollars ($3,000.00). A performance bond shall not be filed unless required by a provision of the power.

§ 34-9-105. Appointment of successor attorneys.

If the attorney-in-fact or any successor dies, ceases to act, refuses or is unable to serve, resigns, fails to maintain or replace a bond, or is removed for cause by a court, a successor attorney-in-fact may be appointed by the principal. If the principal, without having revoked the power of attorney, fails or is unable to appoint a successor within a reasonable time, a judge of the court which approved the power may appoint a successor, unless precluded from doing so by provisions of the original power of attorney. The appointment of a successor attorney-in-fact shall be in writing. If the appointment is by the principal, it is subject to approval by a judge of the court which approved the original power. The original and certified copies of the appointment of the successor shall be filed or recorded as required for an original power of attorney.

§ 34-9-106. Termination of power; inquiries into validity of power; liability of attorney-in-fact.

(a) When power terminates.

A power of attorney terminates on:

(i) Written revocation by the principal;

(ii) Death of the principal;

(iii) Order of a court appointing a guardian, conservator, or committee of the person or property or both of the principal, unless the order otherwise provides;

(iv) Expiration or termination as specified in the power of attorney; or

(v) A determination by a judge of the approving court that the value of the property or the amount of the annual money income covered by the instrument has so increased that this act [§§ 34-9-101 to 34-9-110] is no longer appropriately applicable.

(b) Filing, etc., of instrument terminating power.

The original resignation of an attorney-in-fact, a written revocation of the power of attorney by a principal, or a certified copy of the death certificate of the principal or of the attorney-in-fact or of any court judgment or order terminating the power of attorney or removing the attorney-in-fact for cause, shall be filed promptly in the office of the clerk of the court whose judge approved the power, and certified copies shall be filed or recorded promptly in all offices in which a certified copy of the original power of attorney is filed or recorded. A notation of the terminating event shall be made by the clerk on the face of the original power of attorney.

(c) Inquiries into validity of power.

A person dealing with the attorney-in-fact is not required to inquire into the validity or adequacy of proceedings involving an approval, filing or recording of the power of attorney, to determine whether the power may have been terminated if not yet shown by filing or recordation under subsection (b). He is not required to inquire into the validity or propriety of any act of an attorney-in-fact apparently authorized by his approved power, or to assure the proper application by the attorney-in-fact of any money or property paid or delivered to him.

(d) Liability of attorney; conclusion of duties.

The attorney-in-fact is liable to the principal and the principal's estate for all damage and loss the principal suffers because of the attorney's acts done after the attorney received notice of the termination of his authority or after termination by provision of the power itself. After the power is terminated, he may perform ministerial acts reasonably necessary to complete and conclude his duties.

§ 34-9-107. Limitation on liability.

Unless otherwise provided in the power of attorney, an attorney-in-fact is not liable to his principal or his legal representative except for his intentional wrongdoing or fraud. He is not liable for any wrongdoing of parties with whom he deals in good faith.

§ 34-9-108. Compensation and reimbursement for expenses of attorney-in-fact.

An attorney-in-fact is entitled to reimbursement for his reasonable expenses incurred in the performance of his duties, and, unless precluded by the power of attorney, to reasonable compensation for his services, payable out of the income and assets subject to the power. The amount of compensation and time of payment may be fixed in the power.

§ 34-9-109. Accounting of attorney-in-fact.

An attorney-in-fact shall account to the principal or his legal representative at time specified in the power of attorney, at any time directed by a judge of the approving court, and upon termination of the power or his authority; and he shall deliver promptly to the principal, his legal representative, or a successor attorney-in-fact all property held by him as attorney-in-fact upon termination of the power or his authority.

§ 34-9-110. Scope.

This act governs only powers of attorney executed under it. It does not affect powers of attorney executed under other statutes or the common law of this state.

Wyo. Stat. § 34-9-101 to 110 (1977) (enacted 1965).

Other Proposed Uniform Statutes

Uniform Law Commissioners' Model Health-Care Consent Act*

§ 1. Definitions.

As used in this [Act]:

(1) "Adult" means an individual [18] or more years of age.

(2) "Health care" means any care, treatment, service, or procedure to maintain, diagnose, or treat an indivdual's physical or mental condition.

(3) "Health-care provider" means a person who is licensed, certified or otherwise authorized by the law of this State to administer health care in the ordinary course of business or practice of a profession.

(4) "Minor" means an individual who is not an adult.

(5) "Person" means an individual, corporation, business trust, estate, trust, partnership, association, government, governmental subdivision or agency, or any other legal entity.

§ 2. Individuals who may consent to health care.

Unless incapable of consenting under Section 3, an individual may consent to health care for himself if he is:

(1) an adult; or

(2) a minor and

(i) is emancipated,

(ii) has attained the age of [14] years and, regardless of the source of his income, is living apart from his parents or from an individual in loco parentis and is managing his own affairs,

(iii) is or has been married,

(iv) is in the military service of the United States, or

(v) is authorized to consent to the health care by any other law of this State.

§ 3. Individuals incapable of consenting.

An individual otherwise authorized under this [Act] may consent to health care unless, in the good faith opinion of the health-care provider, the individual is incapable of making a decision regarding the proposed health care.

§ 4. Individuals who may consent to health care for others.

(a) If an individual incapable of consenting under Section 3 has not appointed a health-care representative under Section 6 or the health-care representative appointed under Section 6 is

* National Conference of Commissioners on Uniform State Law, approved and recommended for enactment in all the states at its annual conference, Monterey, California, July 30-Aug. 6, 1982.

not reasonably available or declines to act, consent to health care may be given:

(1) by a guardian of his person, a representative appointed under Section 7, or a representative designated or appointed under other law of this State;

(2) by a spouse, parent, adult child, or adult sibling, unless disqualified under Section 8, if there is no guardian or other representative described in paragraph (1) or he is not reasonably available or declines to act, or his existence is unknown to the health-care provider.

(b) Consent to health care for a minor not authorized to consent under Section 2 may be given:

(1) by a guardian or his person, a representative appointed under Section 7, or a representative designated or appointed under other law of this State;

(2) by a parent or an individual in loco parentis, if there is no guardian or other representative described in paragraph (1) or he is not reasonably available or declines to act, or his existence is unknown to the health-care provider;

(3) by an adult sibling of the minor, if a parent or an individual in loco parentis is not reasonably available, declines to act, or his existence is unknown to the health-care provider.

(c) An individual delegated authority to consent under Section 5 has the same authority and responsibility as the individual delegating the authority.

(d) A person authorized to consent for another under this section shall act in good faith and in the best interest of the individual incapable of consenting.

§ 5. Delegation of power to consent to health care for another.

(a) An individual authorized to consent to health care for another under Section 4(a)(2), 4(b)(2) or 4(b)(3) who for a period of time will not be reasonably available to exercise the authority may delegate the authority to consent during that period to another not disqualified under Section 8. The delegation must be in writing and signed and may specify conditions on the authority delegated. Unless the writing expressly provides otherwise, the delegate may not delegate the authority to another.

(b) The delegate may revoke the delegation at any time by notifying orally or in writing the delegate or the health-care provider.

§ 6. Health-care representative: appointment; qualification; powers; revocation and responsibility.

(a) An individual who may consent to health care under Section 2 may appoint another as a health-care representative to act for the appointor in matters affecting his health care.

(b) A health-care representative appointed under this section must be an individual who may consent to health care under Section 2.

(c) An appointment and any amendment thereto must be in writing, signed by the appointor and a witness other than the health-care representative and accepted in writing by the health-care representative.

(d) The appointor may specify in the writing terms and conditions considered appropriate, including an authorization to the health-care representative to delegate the authroity to consent to another.

(e) The authority granted becomes effective according to the terms of the writing.

(f) The writing may provide that the authority does not commence until, or terminates when, the appointor becomes incapable of consenting. Unless expressly provided otherwise, the authority granted in the writing is not affected if the appointor becomes incapable of consenting.

(g) Unless the writing provides otherwise, a health-care representative appointed under this section who is reasonably available and willing to act has priority to act for the appointor in all matters of health care.

(h) In making all decisions regarding the appointor's health care, a health-care representative appointed under this section shall act (i) in the best interest of the appointor consistent with the purposes expressed in the appointment and (ii) in good faith.

(i) A health-care representative who resigns or is unwilling to comply with the written appointment may exercise no further power under the appointment and shall so inform (i) the appointor, (ii) the appointor's legal representative, if one is known, and (iii) the health-care provider, if the health-care representative knows there is one.

(j) An individual who is capable of consenting to health care may revoke: (i) the appointment at any time by notifying the health-care representative orally or in writing, or (ii) the authority granted to the health-care representative by notifying the health-care provider orally or in writing.

§ 7. Court-ordered health care or court-ordered appointment of a representative.

(a) A health care provider or any interested individual may petition the [_____] court to (i) make a health-care decision or order health care for an individual incapable of consenting or (ii) appoint a representative to act for that individual.

[(b) Reasonable notice of the time and place of hearing a petition under this section msut be given to the individual

incapable of consenting and to individuals in the classes described in Section 4 who are reasonably available.

(c) The court may modify or dispense with notice and hearing if it finds that delay will have a serious, adverse effect upon the health of the individual.]

(d) The court may order health-care, appoint a representative to make a health-care decision for the individual incapable of consenting to health care with such limitations on the authority of the representative as it considers appropraite, or order any other appropriate relief in the best interest of that individual, if it finds:

(1) a health-care decision is required for the individual;

(2) the individual is incapable of consenting to health care; and

(3) there is no individual authorized to consent or an individual authorized to consent to health care is not reasonably available, declines to act, or is not acting in the best interest of the individual in need of health care.

§ 8. Disqualification of authorized individuals.

(a) An individual who may consent to health care for himself under Section 2 may disqualify others from consenting to health care for him.

(b) The disqualification must be in writing, signed by the individual, and designate those disqualified.

(c) A health-care provider who knows of a written disqualification may not accept consent to health care from a disqualified individual.

(d) An individual who knows he has been disqualified to consent to health care for another may not act for the other under this [Act].

§ 9. Limitations of liability.

(a) A health-care provider acting or declining to act in reliance on the consent or refusal of consent of an individual who he believes in good faith is authorized by this [Act] or other law of this State to consent to health care is not subject to criminal prosecution, civil liability, or professional disciplinary action on the ground that the individual who consented or refused to consent lacked authority or capacity.

(b) A health-care provider who believes in good faith an individual is incapable of consenting under Section 3 is not subject to criminal prosecution, civil liability, or professional disciplinary action for failing to follow that individual's direction.

(c) A person who in good faith believes he is authorized to consent or refuse to consent to health care for another under this [Act] or other law of this State is not subject to criminal

prosecution or civil liability on the ground he lacked authority to consent.

§ 10. Availability of medical information.

An individual authorized to consent to health care for another under this Act has the same right as does the individual for whom he is acting to receive information relevant to the contemplated health care and to consent to the disclosure of medical records to a contemplated health-care provider. [Disclosure of information regarding contemplated health care to an individual authorized to consent for another is not a waiver of an evidentiary privilege.]

§ 11. Effect on existing state law.

(a) This [Act] does not affect the law of this State concerning an individual's authorization to make a health-care decision for himself or another to withdraw or withhold medical care necessary to preserve or sustain life.

(b) This [Act] does not affect the requirements of any other law of this State concerning consent to observation, diagnosis, treatment or hospitalization for a mental illness.

(c) This [Act] does not authorize an individual to consent to any health care prohibited by the law of this State.

(d) This [Act] does not affect any requirement of notice to others of proposed health care under any other law of this State.

(e) This [Act] does not affect the law of this State concerning (i) the standard of care of a health-care provider required in the administration of health care, (ii) when consent is required for health care, (iii) informed consent for health care, or (iv) consent to health care in an emergency.

(f) This [Act] does not prevent an individual capable of consenting to health care for himself or another under this [Act], including those authorized under Sections 4, 5 and 6, from consenting to health care administered in good faith pursuant to religious tenets of the individual requiring health care.

§ 12. Severability.

If any provisions of this [Act] or the application hereof to any person or circumstance is held invalid, the invalidity does not affect other provisions or applications of the [Act] which can be given effect without the invalid provision or application, and to this end the provisions of this [Act] are severable.

§ 13. Uniformity of application and construction.

This [Act] shall be applied and construed to effectuate its general purpose to make uniform the law with respect to the subject of this [Act] among states enacting it.

§ 14. Short title.

This [Act] may be cited as the Uniform Law Commissioner's Model Health-Care Consent Act.

§ 15. Repeal.

The following acts and parts of acts are repealed:

(1)

(2)

(3)

§ 16. Time of taking effect.

This [Act] shall take effect _____.

The Uniform Right to Refuse Treatment Act*

§ 1. Definitions

"Competent person" shall mean an individual who is able to understand and appreciate the nature and consequences of a decision to accept or refuse treatment.

"Declaration" shall mean a written statement executed according to the provisions of this Act which sets forth the declarant's intentions with respect to medical procedures, treatment or nontreatment, and may include the declarant's intentions concerning palliative care.

"Declarant" shall mean an individual who executes a declaration under the provisions of this Act.

"Health care provider" shall mean a person, facility or institution licensed to provide health care.

"Incompetent person" shall mean a person who is unable to understand and appreciate the nature and consequences of a decision to accept or refuse treatment.

"Medical procedure or treatment" shall mean any action taken by a physician or health care provider designed to diagnose, assess, or treat a disease, illness, or injury. These include, but are not limited to, surgery, drugs, transfusions, mechanical ventilation, dialysis, resuscitation, artificial feeding, and any other medical act designed for diagnosis, assessment or treatment.

"Palliative care" shall mean any measure taken by a physician or health care provider designed primarily to maintain the patient's comfort. These include, but are not limited to, sedatives and pain-killing drugs; non-artificial, oral feeding; suction; hydration; and hygienic care.

* Legal Advisory Committee (Chairman, George J. Annas, JD, MPH), Concern for Dying, 250 West 57th Street, New York, N.Y. 10101 (May 1982).

"Physician" shall mean any physician responsible for the declarant's care.

§ 2. A competent person has the right to refuse any medical procedure or treatment, and any palliative care measure.

§ 3. A competent person may execute a declaration directing the withholding or withdrawal of any medical procedure or treatment or any palliative care measure, which is in use or may be used in the future in the person's medical care or treatment, even if continuance of the medical procedure or treatment could prevent or postpone the person's death from being caused by the person's disease, illness or injury. The declaration shall be in writing, dated and signed by the declarant in the presence of two witnesses. The two witnesses must sign the declaration, and by their signatures indicate they believe the declarant's execution of the declaration was understanding and voluntary.

§ 4. If a person is unable to sign a declaration due to a physical impairment, the person may execute a declaration by communicating agreement after the declaration has been read to the person in the presence of the two adult witnesses. The two witnesses must sign the declaration, and by their signatures indicate the person is physically impaired so as to be unable to sign the declaration, that the person understands the declaration's terms, and that the person voluntarily agrees to the terms of the declaration.

§ 5. A declarant shall have the right to appoint in the declaration a person authorized to order the administration, withholding, or withdrawal of medical procedures and treatment in the event that the declarant becomes incompetent. A person so authorized shall have the power to enforce the provisions of the declaration and shall be bound to exercise this authority consistent with the declaration and the authorized person's best judgment as to the actual desires and preferences of the declarant. No palliative care measure may be withheld by an authorized person unless explicitly provided for in the declaration. Physicians and health care providers caring for incompetent declarants shall provide such authorized persons all medical information which would be available to the declarant if the declarant were competent.

§ 6. Any declarant may revoke a declaration by destroying or defacing it, executing a written revocation, making an oral revocation, or by any act evidencing the declarant's specific intent to revoke the declaration.

§ 7. A competent person who orders the withholding or withdrawal of treatment shall receive appropriate palliative care unless it is expressly stated by the person orally or through a declaration that the person refuses palliative care.

§ 8. This act shall not impair or supersede a person's legal right to direct the withholding or withdrawal of medical treatment or procedures in any other manner recognized by law.

§ 9. No person shall require anyone to execute a declaration as a condition of enrollment, continuation, or receipt of benefits for disability, life, health or any other type of insurance. The withdrawal or withholding of medical procedures or treatment pursuant to the provisions of this Act shall not affect the validity of any insurance policy, and shall not constitute suicide.

§ 10. This act shall create no presumption concerning the intention of a person who has failed to execute a declaration. The fact that a person has failed to execute a declaration shall not constitute evidence of that person's intent concerning treatment or nontreatment.

§ 11. A declaration made pursuant to this Act, an oral refusal by a person, or a refusal of medical procedures or treatment through an authorized person, shall be binding on all physicians and health care providers caring for the declarant.

§ 12. A physician who fails to comply with a written or oral declaration and to make necessary arrangements to transfer the declarant to another physician who will effectuate the declaration shall be subject to civil liability and professional disciplinary action, including license revocation or suspension. When acting in good faith to effectuate the terms of a declaration or when following the direction of an authorized person appointed in a declaration under Section 5, no physician or health care provider shall be liable in any civil, criminal or administrative action for withholding or withdrawing any medical procedure, treatment, or palliative care measure. When acting in good faith, no witness to a declaration, or person authorized to make treatment decisions under Section 5, shall be liable in any civil, criminal or administrative action.

§ 13. A person found guilty of willfully concealing a declaration, or falsifying or forging a revocation of a declaration, shall be subject to criminal prosecution for a misdemeanor [the class or type of misdemeanor is left to the determination of individual state legislatures].

§ 14. Any person who falsifies or forges a declaration, or who willfully conceals or withholds information concerning the revocation of a declaration, with the intent to cause a withholding or withdrawal of life-sustaining procedures from a person, and who thereby causes life-sustaining procedures to be withheld or withdrawn and death to be hastened, shall be subject to criminal prosecution for a felony [the class or type of felony is left to the determination of individual state legislatures].

§ 15. If any provision or application of this act is held invalid, this invalidity shall not affect other provisions or applications

of the act which can be given effect without the invalid provision or application, and to this end the provisions of this act are severable.

Medical Treatment Decision Act, Michigan House Bill No. 4492 (1981)*

A bill to confirm the right to accept or refuse medical treatment; to provide for the appointment of agents and prescribe their powers and duties; to prescribe certain criminal and civil liabilities; and to provide for certain immunities.

THE PEOPLE OF THE STATE OF MICHIGAN ENACT:

§ 1.

This act shall be known and may be cited as the "medical treatment decision act."

§ 2.

As used in this act:

(a) "Adult person" means a legally competent individual who has attained the age of majority.

(b) "Age of majority" means the age prescribed in section 2 of Act No. 79 of the Public Acts of 1971, being section 722.52 of the Michigan Compiled Laws.

(c) "Agent" means an adult person who is appointed and who accepts an appointment pursuant to section 4.

(d) "Attending physician" means the physician selected by, or assigned to, the patient and who has primary responsibility for the treatment and care of the patient.

(e) "Medical treatment" means a medication, surgical procedure, mechanical life-support system, or other medical therapeutic procedure or device administered by a physician or performed by another health care professional under the direction of a physician.

(f) "Physician" means a person licensed to practice medicine or osteopathic medicine and surgery under article 15 of Act No. 368 of the Public Acts of 1978, as amended, being sections 333.16101 to 333.18838 of the Michigan Compiled Laws.

§ 3.

(1) An adult person has the right to accept or refuse medical treatment in accordance with that person's wishes or desires. This right includes a refusal of medical treatment which would extend the person's life.

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* March 26, 1981, Introduced by Reps. Hollister, Stabenow, Gilmer, Leland, Fitzpatrick, Padden, Jondahl, Evans, and Nash and referred to the Committee on Public Health.

(2) An adult person may appoint an agent who will act on behalf of the appointor if, due to a condition resulting from illness or injury and in the judgment of the attending physician, the appointor becomes incapable of making a decision in the exercise of the right to accept or refuse medical treatment.

(3) An agent may accept or refuse medical treatment for the appointor, if in the judgment of the attending physician the appointor is incapable of making the decision. This authority shall include the right to refuse medical treatment which would extend the appointor's life. An agent authorized to make decisions under this act has a duty to act in good faith and with due regard for the interest and benefit of the appointor. If an agent makes a decision to accept or refuse medical treatment for the appointor, the agent's decision shall be recorded in the appropriate medical record.

(4) The authority of an agent shall not be operative in an emergency situation, if in the judgment of the physician providing or directing the medical treatment of the patient, immediate, initial care is urgently needed to stabilize the patient's condition in response to an unanticipated, acute illness or injury.

(5) The authority of an agent shall not be operative if a court has ordered or authorized medical treatment for the appointor under chapter 4, 5, or 6 of Act No. 258 of the Public Acts of 1974, as amended, being sections 330.1400 to 330.1497, 330.1500 to 330.1541, or 330.1600 to 330.1642 of the Michigan Compiled Laws.

§ 4.

(1) An adult person may appoint an agent to accept or refuse medical treatment on behalf of the appointor by signing a document to that effect. An adult person may appoint alternate agents to serve if the first named agent is unavailable. Only a single agent shall have authority for medical decision making at a time. With respect to medical treatment for an appointor, the decision of an agent shall prevail over that of a guardian of the person appointed by the probate court, except as provided in section 3(5). The order of authority shall devolve to alternate agents in the order prescribed in the document.

(2) The document shall conform to the following form:

"Appointment of Agent for Medical Treatment Decision
I, the undersigned, this _____ day of _____, 19 _____, being of sound mind, willfully and voluntarily appoint (legal name), whose current telephone number and address are (telephone number), (street and number), (city and state), to accept or refuse medical treatment on my behalf and in my interest if, due to a condition resulting from illness or injury, and in the judgment of the attending physi-

cian, I become incapable of making a decision in exercise of my right to accept or refuse medical treatment.

If the appointee named in the preceding paragraph is unavailable to make a decision, I appoint (legal name), whose current telephone number and address are (telphone number), (street and number), (city state), as an alternate agent to make the decision.

Signed _____

Address _____

The person signing this document is known to me, and I believe him or her to have wilfully and voluntarily signed this document.

Witness _____

Address _____

date _____

Witness _____

Address _____

date _____

Acceptance by Agent or Alternate Agent, or Both

As agent or alternate agent I understand that acceptance of this appointment means that I have a duty to act in good faith and with due regard for the interest and benefit of the person appointing me:

Agent's signature _____

date _____

Alternate agent's signature _____

date _____. "

(3) The adult person appointing an agent or an agent and 1 or more alternate agents pursuant to subsection (2) shall prepare copies of the document for each agent and alternate agent. After the appointor individually signs each copy and the signature is witnessed, the copies shall be presented to the agent and alternate agents. Upon signing the document, the agent shall be eligible to assume the authority and duties prescribed in section 3(3). One copy shall be kept by the appointor and each agent or alternate agent. A duplicate of the signed copies may be given to a physician or to other persons according to the wishes of the appointor. The agent may refuse to accept this authority, at any time following receipt of the document, by writing a statement to that effect on the document and returning the document to the appointor. If the appointor of the document comes into the care of a physician who does not possess a copy, and the conditions for effectuating the agreement are considered to be present, the agent or alternate agent shall provide the attending physician with a copy of the signed agreement. The attending physician can make the document a part of the medical record.

(4) For purposes of this section, if the appointor is institutionalized in, or receiving care at, an extended care facility, nursing home, or hospital, a witness to the appointment of an agent or alternate agent shall not have a proprietary interest in, nor be an employee of, or a person acting on behalf of, the facility, nursing home, or hospital.

(5) A person who is a representative, employee, or officer of a private or public agency, organization, or institution shall not accept appointment as an agent or serve as an agent solely because of that person's capacity as a representative, employee, or officer.

§ 5.

(1) An appointor may revoke the appointment at any time, regardless of mental state or competency, by writing a statement of revocation, by defacing or destroying the document, or by making an oral statement of revocation in the presence of 2 or more witnesses.

(2) A subsequent appointment made by signing a document described in section 4 shall operate to revoke a prior appointment.

(3) A person who has knowledge of a revocation shall notify the attending physician, the agent, and the alternate agent.

§ 6.

(1) An agent who makes a decision regarding the acceptance or refusal of medical treatment for the appointor shall not be civilly or criminally liable for the act of accepting or refusing medical treatment, or for the consequences of the act, if both of the following conditions are met:

(a) The agent makes the decision in accordance with the degree of care reasonably expected of a person who has a duty to act in good faith and with due regard for the interest and benefit of the appointing person.

(b) The agent's decision does not violate this act or the civil or criminal laws of this state.

(2) An agent shall not be civilly or criminally liable for failure to observe a revocation made pursuant to section 5 unless that agent had actual knowledge of the revocation.

§ 7.

(1) A person who is not an agent, and who attempts to act as an agent or otherwise represents himself or herself as an agent, is criminally liable for the attempted action or the representation.

(2) A person who knowingly conceal a revocation of his or her appointment as an agent and who attempts to act as an agent or otherwise represents himself or herself as agent, is criminally liable for the attempted action or the representation.

(3) A person who falsely represents himself or herself as an agent or who knowingly conceals a revocation of his or her appointment as an agent, and who gives instructions for the refusal of medical treatment with the intent of hastening a patient's death, is liable for prosecution for homicide.

§ 8.

(1) A person shall not accept remuneration for services performed as an agent under this act.

(2) A person shall not solicit another to be appinted as the latter's agent under this act.

(3) A person who violates this section is guilty of a misdemeanor.

§ 9.

(1) This act shall not preclude an adult person from preparing written instructions for his or her medical treatment. The written instructions are advisory and are evidence of the person's wishes and interests. However, if the adult person appoints an agent, the decision of the agent shall prevail over written instructions prepared pursuant to this section.

(2) The written instructions shall be signed by the originator of the instructions in the presence of 2 witnesses who, by their signatures, shall affirm that the originator wilfully and voluntarily signed the instructions.

(3) For purposes of this section, if the person preparing and signing the written instructions is institutionalized in, or receiving care at, an extended care facility, nursing home, or hospital, a witness to the signing of the written instructions shall not have a proprietary interest in, nor be an employee or person acting on behalf of, the facility, nursing home, or hospital.

(4) An adult person who prepares and signs written instructions pursuant to this section may revoke the instructions at any time, regardless of mental state or competency, by writing a statement of revocation, by defacing or destroying the instructions, or by making an oral statement of revocation in the presence of 2 or more witnesses.

(5) The preparation and signing of written instructions shall operate to revoke any prior written instructions.

(6) If the person preparing and signing written instructions has not appointed an agent, a physician or other health care professional acting under the direction of a physician shall not be civilly or criminally liable for acting in accordance with written instructions, if following the written instructions does not violate this act or the civil or criminal laws of this state.

§ 10.

(1) A person shall not be required to appoint an agent issuance of an insurance policy or as a condition to receiving health care services.

(2) The appointment of an agent or the preparation and signing of written instructions pursuant to section 9 shall not restrict the sale, procurement, or issuance of an insurance policy. The appointment of an agent or the preparation and signing of written instructions shall not be considered to modify the terms of an existing insurance policy. An insurance policy shall not be impaired or invalidated by the withholding or withdrawal of medical treatment pursuant to this act, notwithstanding a term of the policy to the contrary.

§ 11.

(1) The death of an adult person which results from or follows the withholding or withdrawal of medical treatment pursuant to this act shall not constitute a suicide.

(2) This act shall not be construed to condone, authorize, or approve mercy killing or suicide.

§ 12.

(1) A physician or other health care professional acting under the direction of a physician who administers, withholds, or withdraws medical treatment upon the request of a person reasonably believed to be an agent shall not be civilly or criminally liable for the act of administering, withholding, or withdrawing the medical treatment if the request of the agent does not violate this act or the civil or criminal laws of this state. The burden of proof regarding the reasonable belief of the physician or other health care professional acting under the direction of a physician with regard to the identity of the agent shall be upon the person contesting the reasonable belief.

(2) A physician or other health care professional acting under the direction of a physician who fails to observe a refusal of medical treatment or a request for continued medical treatment by an agent shall be legally liable in the same manner and degree as would have been the case if the appointor had been capable of making the decision and had refused or requested the treatment in his or her own right under similar circumstances.

§ 13.

Health care personnel shall not be required to participate in the treatment or care of a patient pursuant to this act, if they find the treatment or care morally objectionable, and if they withdraw from the case after informing the patient or agent, or both, and other appropriate health care personnel of their withdrawal and after finding a replacement.

§ 14.

This act shall not affect the rights of a person to accept or refuse medical treatment, if that person has neither appointed an agent nor prepared and signed written instructions pursuant to section 9.

§ 15.

(1) The circuit court has jurisdiction over an action to remove an agent appointed under this act. A relative or guardian of the appointor, a physician providing medical treatment to the appointor, or an officer or employee of a health facility or institution at which the appointor is receiving medical treatment may bring an action to seek temporary or permanent removal of an agent who fails to act in a manner consistent with the authority and duties prescribed in section 3(3) and 6(1). The plaintiff shall bear the burden of proof in an action brought under this subsection.

(2) The circuit court has jurisdiction over an action contesting the interpretation or validity of written instructions prepared and signed pursuant to section 9.

(3) A party to a proceeding brought under this section may request an expedited hearing as provided by court rule.

Hospital Ethics Committees: Proposed Statute and National Survey

F

A Model Bill to Establish Hospital Ethics Committees*

§ 1: Definitions

A) Hospital. "Hospital" includes any facility that provides in-patient care.

B) Treatment. "Treatment" includes both life-prolonging and life-saving procedures, whether surgical, pharmaceutical or mechanical.

C) Incompetent Patient. "Incompetent patient" includes an adult person without sufficient mental capacity or reason to understand the nature and consequences of a medical procedure offered when the person must decide whether to accept or reject that procedure.

D) Case Record. "Case Record"means that record that the hospital ethics committee assembles when it reviews a decision made by or for a patient. The case record includes the patient's medical record, a summary of the opinions of consulting physicians, the hospital ethics committee meeting minutes, and the hospital ethics committee's written recommendation.

§ 2: Scope of the Hospital Ethics Committee's Authority

A) Any hospital may establish a hospital ethics committee ("committee").

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* The Model Bill presented here was prepared for the American Society of Law & Medicine (765 Commonwealth Ave., 16th Floor, Boston, Mass. 02215) by Mary Beth Prosnitz of the Boston University School of Law Legislative Services. The Society does not necessarily recommend or support the positions or approach contained therein.

B) The committee shall perform the following functions:

1) **Review treatment decisions made on behalf of terminally ill incompetent patients, and review treatment decisions made by terminally ill competent patients who request committee review.** The committee shall confirm the competence of the patient and shall determine whether the patient has a terminal illness. The committee shall discuss the decision with the patient, the patient's family, the responsible physician and the patient's guardian, if the patient has recieved a court appointed guardian. The committee may consult with any additional physicians or specialists it desires during its review of the treatment decision. The committee shall arrive at a non-binding advisory recommendation describing the appropriate treatment for the patient. If the incompetent patient's family, the responsible physician or the incompetent patient's guardian disagree with the committee's recommendation, or if the competent patient disagrees with the committee's recommendation, the committee shall refer the case to a court of proper jurisdiction for resolution. If the committee refers a case to court for resolution, the committee shall submit its case record to the court.

2) **Review medical decisions having ethical implications.** Any competent patient, member of a patient's family, physician or hospital staff person may request committee review of any medical decision made in the hospital that has ethical implications. The committee shall grant each request for review unless another hospital agency can review the decision more effectively. The committee shall inform the patient whose case it reviews of the committee's consideration of his/her case. The committee shall discuss the decision with the patient, the patient's family, the responsible physician and the patient's guardian, if the patient has received a court appointed guardian. In addition, the committee shall discuss the case with the hospital staff person if that person requested committee review of the decision. The committee may consult with any additional physicians or specialists it desires during its review of the decision. The committee shall arrive at a non-binding advisory recommendation describing the appropriate course of action for the patient. If the competent patient's decision and the committee's recommendation disagree, the committee shall refer the case to a court of proper jurisdiction for resolution. If the committee refers a case to a court for resolution, the committee shall submit its case record to the court.

3) **Provide counseling.** Any patient, member of a patient's family, physician, or hospital staff person may approach the committee or any of its members for social, psychological, spiritual or other counseling. The committee or the individual committee member shall provide the requested counseling or shall refer the person requesting counseling to another person or agency qualified to provide the requested counseling.

C) The committee may perform the following functions:

1) **Establish guidelines.** The committee may establish guidelines regarding treatment or any other medical decisions in cooperation with the hospital staff, administration and local professional organizations.

2) **Provide education.** The committee may sponsor or conduct educational programs designed to inform the hospital staff, administration and the general public about ethical problems in the health care field.

§ 3: Immunity.

A) Committee members shall have complete civil and criminal immunity from liability for committee recommendations made within the scope of the committee's authority, provided that the committee operates according to the provisions set forth in Section 4.

B) The hospital staff, administration and the responsible physician shall have the benefit of a presumption of freedom from civil and criminal liability for their actions taken in accordance with the committee's recommendation. Proof of gross negligence or wilfull disregard of the patient's interests overcomes this presumption.

§ 4: Administration.

A) **Committee members.**

1) **Composition of the committee.** The committee shall consist of nine members: two physicians, one an internist, the other a subspecialist; an attorney; a hospital administrator; a social worker; a psychiatrist; a member of the clergy; an advocate for patients; and a hospital volunteer or other appropriate representative of the community served by the hospital.

2) **Selection of committee members.** The chief hospital administrator shall request nominations for committee memberships from the hospital staff. The chief hospital administrator shall then appoint nine committee members from the group of nominees. The chief hospital administrator shall ensure that the nine members represent the nine positions listed in Section 4 A)1) above, but he/she may appoint members for the committee who do not serve on the hospital staff if a particular discipline has no members among the hospital staff.

3) **Term.** Each committee member shall serve a term of one year on the committee, though any member may serve more than one term as a committee member. The chief hospital administrator shall establish a system of staggered terms for the committee members so that no more than three member's terms expire on the same date.

B) **Committee proceedings.**

1) The committee may draft its own by-laws consistent with this statute and may appoint officers.

2) The committee shall convene within three days of a request for committee review of a treatment or other medical decision.

3) The committee shall keep minutes of its meetings. These minutes shall summarize the deliberations of the committee made in arriving at a recommendation.

4) The committee shall arrive at a recommendation by majority vote.

5) Any patient, member of a patient's family, physician, or hospital staff person may attend committee meetings for the purpose of presenting issues for the committee's consideration. Only committee members shall attend that part of the committee meeting during which the committee members discuss the case in an attempt to reach a recommendation.

C) **Notice.**

1) The hospital shall inform all patients admitted to the hospital about the committee and its functions and the means of patient access to the committee.

2) The committee shall place a copy of its recommendation in the patient's hospital record. The responsible physician shall verbally inform the patient of the committee's recommendation in an appropriate manner, taking the patient's mental status and physical condition into consideration.

3) The person who requested committee review of a treatment or other medical decision shall receive a copy of the committee's recommendation.

A National Survey of Hospital Ethics Committees*

Introduction

American medicine and society in general have, in the past decade, been forced to confront a growing problem: deciding whether to withhold or withdraw increasingly sophisticated life-support systems from patients whose future quality of life is questionable. Such decisionmaking inevitably raises complicated clinical questions, as well as legal, ethical, and social issues. The formation of hospital "ethics" committees (also referred to as prognosis, terminal care, and/or optimum care committees) has been one response to the problem. Little is known about the number and specific roles of these committees. Robert Veatch points out, "Hospital ethics committees are a new development, and it is still unclear which types will gain support and how they will evolve."[1] This study is a preliminary attempt to assess the prevalence, stated purposes, operating characteristics, and perceived effectiveness of "ethics" committees in hospitals across the continental United States.

Background

Unlike Institutional Review Boards (established by mandate according to Federal guidelines) or the early hemodialysis committees (specifically created to select patients to receive a scarce medical resource), hospital ethics committees arose independently, for a variety of reasons.

The New Jersey Supreme Court's 1976 ruling on the Karen Quinlan case was one of the early influences on the formulation of ethics committees. The Court said that the patient's guardian, family, and physician

> shall consult with the hospital "Ethics Committee" or like body of the institution in which Karen is then hospitalized. If that consultative body agrees that there is no reasonable possibility of Karen's ever emerging from her present comatose condition to a cognitive,

* by Stuart J. Youngner, M.D. (Assistant Professor of Psychiatry), David L. Jackson, M.D., Ph.D. (Associate Professor of Medicine and Neurology and Director, Center for the Critically Ill), Claudia Coulton, Ph.D. (Associate Professor, School of Applied Social Sciences), Barbara W. Juknialis, M.A. (Research Associate, Center for the Critically Ill), and Era Smith (Research Assistant, Center for the Critically Ill), all from Case Western Reserve University School of Medicine, Cleveland, Ohio. This survey was done under contract with the President's Commission.

[1] Robert M. Veatch, *Hospital Ethics Committees: Is There a Role?*, 7 HASTINGS CTR. REP. 22, 25 (June 1977).

> sapient state, the present life-support system may be withdrawn and said action shall be without any civil or criminal liability therefore on the part of any participant, whether guardian, physician, hospital or others.[2]

The New Jersey Supreme Court's effort to clarify the decisionmaking process has received considerable criticism. George Annas considered the decision "legal comfort for doctors," and commented further, "Its looseness of language and potential for abuse demand to be exposed and discussed."[3] Carol Levine stated, "Ethics committees have received much attention as an aftermath of the Quinlan decision, but confusion rather than clarification has been the result."[4]

By calling it an "ethics" committee but assigning it a prognostic function, the Court has created confusion about the committee's role. Robert Veatch,[5] and Harold Hirsch and Richard Donovan[6] explore its possible roles—*e.g.*, determine prognosis; make ethically sound decisions; give counseling and support to medical staff, patients, and families; make larger ethical policy decisions for hospitals; provide legal protection for physicians and hospitals. The problems attending each of these roles have been identified and discussed.

There is concern that committee composition and membership, as well as access to committee meetings, will be dominated and controlled by health professionals—especially physicians. The perceived danger is that health professionals may have values or interests that potentially conflict with those of their patients. Such a conflict of interest may lead to decisions that protect the interests of health professionals or institutions, rather than those of patients. Furthermore, committees, by their very nature, may have detrimental effects by diffusing responsibility and failing to be responsive to crisis situations demanding immediate decisions.

A group from Massachusetts General Hospital in Boston reported on the intended role and actual functioning of one such committee,[7] which had met 21 times in three years.[8] Its main benefits were "clarification of misunderstanding about

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[2] *In re* Quinlan: 70 N.J. 10, 355 A.2d 647, 671 *cert. denied*, 429 U.S. 922 (1976).

[3] George J. Annas, *In re Quinlan: Legal Comfort for Doctors*, 7 Hastings Ctr. Rep. 29, 31 (June 1976).

[4] Carol Levine, *Hospital Ethics Committees: A Guarded Prognosis*, 7 Hastings Ctr. Rep. 25, 26 (June 1977).

[5] Veatch, *supra* note 1.

[6] Harold L. Hirsch and Richard Donovan, *The Right to Die: Medico-Legal Implications of In re Quinlan*, 30 Rutgers L. Rev. 267 (1977).

[7] *Optimum Care for Hopelessly Ill Patients: A Report of the Clinical Care Committee of the Massachusetts General Hospital*, 295 New Eng. J. Med. 362 (1976).

[8] Levine, *supra* note 4, at 26.

the patient's prognosis, reopening of communication, re-establishment of unified treatment objectives and rationale, restoration of the sense of shared responsibility for patient and family, and, above all, maximizing support for the responsible physician who makes the medical decision..."[9]

Methodology

Definition of Committees. An ethics committee, as defined in this study, had to have the potential to become involved in the decisionmaking process in specific cases. The committee's involvement had to precede any final decision about withholding or withdrawing life support in an individual case. The nature of this involvement was not specified, nor were committees with additional functions (**e.g.**, policymaking or teaching) excluded.

Sampling Procedure. The study sample was drawn from the list of 6186 hospitals registered with the American Hospital Association; this figure represents more than 97% of the total number of hospitals in the United States. Freestanding psychiatric and rehabilitation hospitals were excluded from the listed population.

A disproportional, stratified random sampling procedure was used. The population of hospitals was divided into two strata based on the number of acute care beds. A random sample of 202 hospitals was drawn from the population of 4354 small (200 or fewer beds) hospitals. Four hundred hospitals were randomly selected from the population of 1832 large (more than 200 beds) hospitals. Hospital characteristics were taken from the American Hospital Association's Guide.[10]

This sampling procedure was designed to increase the potential number of committees eligible for our later, detailed survey of committee functioning. Since it was expected that substantially more committees would be found in large hospitals, more of them were included in the study. Because of this disproportional sampling procedure, estimates of population parameters had to be based on a reweighted sample.

Design and Measures. Data collection involved two phases. First, the hospitals in the sample were contacted by telephone to determine whether there was an ethics committee. Questions were directed to the Chief of Staff's office, the Director of Nursing, or some member of the hospital administration. As a reliability check, two of the investigators tele-

[9] *Optimum Care for Hopelessly Ill Patients: A Report of the Clinical Care Committee of the Massachusetts General Hospital, supra* note 7, at 364.

[10] American Hospital Association Guide to the Health Care Field, American Hospital Association, Chicago (1981).

phoned the Medical Chiefs of Staff of a random subsample of 30 hospitals—none of which had reported having committees in the initial survey. There was 100% agreement between first and second contacts. This increased the probability that the data were not confounded by false negative responses.

Additional measures were employed to minimize false positive responses. One of the investigators had a phone conversation with the chairperson of each ethics committee identified in the initial survey. This contact verified the existence and function of the committee and requested the chairperson to complete a detailed questionnaire on the committee's functions. The verification eliminated 2 of the 25 hospitals initially identified as having committees. In both cases, the committees were only involved in long-range policy decisions. Detailed questionnaires were then sent to the remaining 23 committee chairpersons. After reviewing the completed questionnaires, 6 more committees were eliminated as false positives because they did not meet our criteria.

The questionnaire included questions about the committee's structure, procedures, activities, and effectiveness. Most questionnaire items were taken from the survey instrument developed and tested by the authors for use in a comprehensive study of a local ethics committee. Test-retest studies on this instrument demonstrated that at least 80% of the respondents gave the same answer to each item on both occasions. All multi-item scale reliabilities exceeded .80 (coefficient alpha). The response rate for the questionnaire portion of the study was 100%.

Results

Prevalence and Distribution of Committees. Ethics committees were found in 17 (4.3%) of the 400 sample hospitals with more than 200 beds. There were no ethics committees found in the 202 hospitals with fewer than 200 beds. The smallest hospital with a committee had 235 beds; several hospitals with more than 1000 beds did not have committees. After weighting the sample elements to compensate for disproportionate probability of inclusion, we estimate that approximately 1% of all hospitals in the United States have ethics committees.

The ethics committees identified in this study were clustered in the Northeast and Atlantic states, the industrial Midwest, and the Far West (see Table F1). Seven (41%) of the hospitals with committees were in New Jersey; this group comprises 39% of the New Jersey hospitals with more than 200 beds which were sampled.

Hospitals with Committees versus Hospitals without Committees. Larger hospitals, particularly those with teaching programs, were the most likely to have ethics committees:

64.7% of the hospitals with committees were teaching hospitals; only 35.2% of the entire sample had teaching programs. The mean number of beds in the hospitals with committees was 485, compared with a mean of 298 in hospitals without committees. Religious affiliation and public versus private administration did not significantly affect the likelihood of having a committee.

Characteristics of Committees. Physicians were the most prevalent members of ethics committees, accounting for approximately 57% of the total membership; three committees were composed entirely of physicians. The majority of committees (14) included at least one member of the clergy and two or three members of other professions. Hospital administrators were more frequently represented than nurses. The various categories of health professionals are listed in Table F2, ranked according to the frequency of committee membership. Committee size ranged from 3 to 23 members, with a median of 8.

The typical ethics committee was formed in 1977, although one was established in 1973 and another in 1982 (mean number of years in existence = 5.7). Committees reviewed an average of approximately one case per year. Three recently established committees had reviewed no cases. The most frequently utilized committee was formed in 1973, and reviewed an average of 2.25 cases per year.

The **Quinlan** decision prompted the formation of 71% of the committees in New Jersey, but only 10% of those in other states. As shown in Table F3, most committees were based on several formally stated purposes that tended to coincide with the actual committee activities. Most committees' deliberations resulted in consultation and advice (81.3%) rather than binding decisions. Committees generally communicated advice as a committee consensus (62.5%), as opposed to having members state their individual opinions (18.8%).

Committee meetings were generally open to responsible physicians, clergy, social workers, and nurses (see Table F4). The right to request a committee meeting was usually limited to attending physicians and to patients' families. Guidelines permitted patient attendance in 19% of the committees; patients could request meetings in 25% of the committees.

Perceived Effectiveness of Committees. Uniformly positive responses were given to questions about committee effectiveness. Major reported benefits were: facilitating decisionmaking by clarifying important issues (73.3%); providing legal protection for hospital and medical staff (60%); shaping consistent hospital policies with regard to life support (56.3%); providing opportunities for professionals to air disagreements (46.7%). Increasing patients' and families' abilities to influence decisions and educating professionals about issues relevant to life-

support decisions were areas in which committees were generally viewed as less effective.

This generally positive view of committee functioning was corroborated by responses to a usefulness index, calculated from the answers to 8 questions, with a possible total score range of 8-40. Actual scores ranged from 29-40. Scores of 24 and above reflected a very positive assessment of the committee's value.

Conclusions

Our study resulted in two important conclusions about hospital "ethics" committees:

> (1) They have not been widely adopted as a means of handling medical ethical problems. Only 1% of the hospitals in this country—none with fewer than 200 beds—have such committees. Furthermore, committees that do exist are not involved in large numbers of cases. Existing committees reviewed an average of only one case per year.
>
> (2) The composition and function of committees identified in this survey would not allay many of the concerns of patients' rights advocates about patient representation and control. Committees were clearly dominated by physicians and other health professionals. The majority of committees did not allow patients to attend or request meetings, although family members were more often permitted to do so. Yet chairmen generally regarded their committees as effective.

Although these may have been "defensive" evaluations, many felt their committees had helped clarify important issues, shape consistent policies, provide opportunities to air disagreements, and protect hospitals and health professionals from legal actions.

Hospitals without committees seemed generally interested in and aware of medical ethical issues. Comments such as "We are working on it" or "Send us your results, maybe they will help us decide what to do" were common. A committee member from a hospital not included in our study suggested that the low number of meetings did not accurately reflect the committee's full impact. "Our committee meetings served as a model. Now each Intensive Care Unit meets to discuss difficult cases. They do not need to call the committee any longer."[11]

With no clear mandate from the courts, legislatures, or Federal government, 1% of U.S. hospitals have established

[11] Personal communication from Elizabeth Heckathorn, R.N., who served on the Ethics Committee at Massachusetts General Hospital, to Stuart Youngner (March 26, 1981).

ethics committees to help make decisions about withholding or stopping life support. Furthermore, the committees identified in this study reviewed very few cases. Although the explanation of these findings is beyond the scope of this study, it is worth pursuing. Were these committees established merely for "cosmetic" reasons? Are there important political and social forces in hospitals that have hampered their formation and function? Or are they simply neither needed nor useful? Have hospitals found other formal or informal mechanisms for solving ethical dilemmas? Will publicity about "successful" committees lead to their wider use? More detailed studies are needed to answer these important questions.

Table F1:

Geographic Distribution of Hospital with Committees

Location*	Number of Hospitals with Committees
Northeast/Atlantic	
Massachusetts (20)	1
New Jersey (18)	7
Pennsylvania (34)	1
Maryland (10)	1
Industrial Midwest	
Illinois (31)	1
Michigan (24)	1
West Coast	
California (56)	2
Oregon (4)	1
Midwest	
Kansas (11)	1
Missouri (11)	1

* Numbers in parentheses refer to the total number of hospitals surveyed in the state.

Table F2:

Committee Membership

Member Category	Median Number of Members Per Committee	Number (and Percent) of Committees Reporting At Least One Member in This Category
Physician	5.25	17 (100%)
Clergy	1.05	14 (82%)
Administrator	.58	9 (53%)
Nurse	.44	8 (47%)
Attorney	.35	7 (41%)
Social worker	.21	5 (29%)
Laypersons	.15	4 (24%)
House officers	.07	2 (12%)
Other	.07	2 (12%)

Table F3:

Committee Purpose

Purpose	Percent Classifying This as a Stated Purpose*	Percent Classifying This as an Actual Function*
Provide counsel and support to physicians	59% (10)	69% (11)
Make ethical/social policy for care of critically ill	47% (8)	38% (6)
Review ethical issues in patient care decisions	53% (9)	56% (9)
Provide counsel and support to other professionals	35% (6)	31% (5)
Determine medical prognosis	29% (5)	25% (4)
Provide counsel and support to patients and families	29% (5)	31% (5)
Make final decisions about life support	18% (3)	31% (5)
Determine continuing education needs	18% (3)	19% (3)
Other	12% (2)	12% (2)

* Numbers in parentheses refer to frequency of response.

Table F4:

Persons Involved in Convening and Attending Meetings

Category	Percent Indicating This Person Could Attend Meetings*	Percent Indicating This Person Could Request a Meeting*
Physician in charge of case	100% (16)	100% (16)
Clergy	56% (9)	31% (5)
Social Worker	50% (8)	19% (3)
Nurse	50% (8)	31% (5)
Patient's family	44% (7)	62% (10)
Lawyer for patient/family	38% (6)	25% (4)
Other physician	25% (4)	38% (6)
Patient	19% (3)	25% (4)
Medical students	12% (2)	12% (2)
Other person	19% (3)	19% (3)

* Numbers in parentheses refer to frequencies. Percentages are adjusted for missing data.

PCEMR STUDY QUESTIONNAIRE

Institution:_____ Date:_____

Respondent: _____

1. What is the name of the ethics committee at your institution?

2. When was it established--i.e., month, year?_____

3. Since its formation, how many cases have been reviewed by your committee?_____

4. How many committee members are there, and what are their professions?

a.	Number of physicians	_____
b.	Number of nurses	_____
c.	Number of house officers	_____
d.	Number of administrators	_____
e.	Number of clergy	_____
f.	Number of psychiatrists	_____
g.	Number of social workers	_____
h.	Number of lawyers	_____
i.	Number of psychologists	_____
j.	Number of lay persons	_____
k.	Other (specify)	_____
	_____	_____
	TOTAL NUMBER OF MEMBERS	_____

5. Who initiated the formation of your ethics committee? (Check all that apply)

_____a. Administration
_____b. Physicians
_____c. Nurses
_____d. Other (specify) _____
_____e. Don't Know

6A. What do you believe was the primary stimulus for the formation of the committee? (Choose one)

_____a. The Quinlan decision
_____b. Clinical need
_____c. Ethical need
_____d. Other (specify) _____
_____e. Don't Know

If "b" or "c" are selected, what was the specific need? _____

6B. To what extent does your committee meet this need? (Choose one)

_____a. Completely
_____b. Mostly
_____c. Partially
_____d. Not at all
_____e. Don't Know

7A. What is the committee's formally stated purpose? (Choose all that apply. Feel free to make additions to the list as appropriate.)

_____a. To determine medical prognosis
_____b. To review ethical issues in patient care decisions in order to make appropriate recommendations for changes
_____c. To provide counsel and support to patients/families
_____d. To provide counsel and support to physicians
_____e. To provide counsel and support to other health professionals
_____f. To make ethical and/or social policy for the care of seriously ill and dying patients treated at the hospital
_____g. To determine continuing educational needs of personnel involved in patient care in the area of terminal care
_____h. To make the final decision about continuing life support
_____i. Other (specify) _____
_____j. Don't Know

7B. Which of the following purposes have actually been served by the committee? (Choose all that apply)

_____a. To determine medical prognosis
_____b. To review ethical issues in patient care decisions in order to make appropriate recommendations for changes
_____c. To provide counsel and support to patients/families
_____d. To provide counsel and support to physicians
_____e. To provide counsel and support to other health professionals
_____f. To make ethical and/or social policy for the care of seriously ill and dying patients treated at the hospital
_____g. To determine continuing educational needs of personnel involved in patient care in the area of terminal care
_____h. To make the final decision about continuing life support
_____i. Other (specify) _____

8. What role does your committee play in decisionmaking? (Choose one)

_____a. Provides consultation and advice
_____b. Makes the final decision
_____c. Both a and b
_____d. Don't Know

9. If your committee is advisory, how is the advice given? (Choose one)

_____a. The committee chairperson communicates a "consensus"
_____b. Each committee member communicates his/her own opinion
_____c. Both a and b
_____d. Other (specify) _____
_____e. Don't Know
_____f. Not Applicable

10. If your committee makes decisions, how are they made? (Choose one)

_____a. Simple majority vote
_____b. Unanimous vote
_____c. Other (specify) _____
_____d. Don't Know
_____e. Not Applicable

11. Who is officially permitted to request a committee meeting? (Choose all that apply)

_____a. Physician in charge of the case
_____b. Any physician
_____c. Nurse
_____d. Medical students
_____e. Clergy
_____f. Lawyer representing patient or family
_____g. Patient's family
_____h. Social worker
_____i. Patient
_____j. Other (specify) _____
_____k. Don't Know

12. Who is officially permitted to attend the committee meetings? (Choose all that apply)

_____a. Physician in charge of the case
_____b. Any physician
_____c. Nurse
_____d. Medical students
_____e. Clergy
_____f. Lawyer representing patient or family
_____g. Patient's family
_____h. Social worker
_____i. Patient
_____j. Other (specify) _____
_____k. Don't Know

13A. How has your committee affected the frequency of court involvement in life support decisions?

_____a. Increased frequency of court involvement
_____b. No impact on court involvement
_____c. Decreased frequency of court involvement
_____d. Don't Know

13B. Do you consider this a beneficial or detrimental effect?

_____Beneficial _____Detrimental _____Don't Know
Explain:

14A. How has your committee affected the frequency of decisions to withhold or discontinue life support?

_____a. Increased frequency of such decisions
_____b. No impact on frequency of such decisions
_____c. Decreased frequency of such decisions
_____d. Don't Know

14B. Do you consider this a beneficial or detrimental effect?

_____Beneficial _____Detrimental _____Don't Know
Explain:

15A. How has your committee affected the speed with which life support has been discontinued?

_____a. Increased the speed
_____b. No impact on the speed
_____c. Decreased the speed
_____d. Don't Know

15B. Do you consider this a beneficial or detrimental effect?

_____Beneficial _____Detrimental _____Don't Know
Explain:

16A. Please rank the following groups according to the amount of help received from the committee. Use "1" to indicate the group that received the greatest amount of help; "4" indicates the group that received the least help.

_____Nurses
_____Physicians
_____Patients' Families
_____Patients

16B. Please explain the ways in which the committee has been helpful or detrimental to each of these groups:

Nurses

Physicians

Patients' Families

Patients

17. What kind of effect has your committee had on each of the following?

A. Shaping or evolving consistent hospital policies with regard to life support

_____Beneficial _____No Impact _____Detrimental _____Don't Know

B. Educating professional staff about the important issues involved in life support

_____Beneficial _____No Impact _____Detrimental _____Don't Know

C. Facilitating decisionmaking by clarifying important issues

_____Beneficial _____No Impact _____Detrimental _____Don't Know

D. Providing legal protection for hosptial and medical staff

_____Beneficial _____No Impact _____Detrimental _____Don't Know

E. Providing an opportunity for health professionals who usually have less power in decisionmaking than physicians to air disagreements, give input, and receive explanations

_____Beneficial _____No Impact _____Detrimental _____Don't Know

F. Increasing the ability of individual patients and families to influence the decisionmaking process

_____Beneficial _____No Impact _____Detrimental _____Don't Know

18. In which of the areas mentioned in Question 17 has the committee had the most positive impact? (Enter the letter preceding the appropriate item in Question 17.)

19. In which of the areas mentioned in Question 17 has the committee had the most negative impact? (Enter the letter preceding the appropriate item in Question 17.)

The following statements deal with the Committee's usefulness in cases that have been reviewed. For each question, please check the answer that best reflects your opinion. (SA=strongly agree; A=agree; U=undecided; D=disagree; SD=strongly disagree)

	SA	A	U	D	SD
The Committee has:					
20. Provided support for families making difficult decisions.	___	___	___	___	___
21. Increased stress for staff.	___	___	___	___	___
22. Increased stress for families.	___	___	___	___	___
23. Provided legal protection for the hospital and medical staff.	___	___	___	___	___
24. Provided support for staff making difficult decisions.	___	___	___	___	___
25. Been a waste of time.	___	___	___	___	___
26. Stirred up trouble among staff.	___	___	___	___	___
27. Come up with good answers to tough questions.	___	___	___	___	___

28. What has been the committee's overall effect on patient care? (Choose one)

_____a. Very beneficial
_____b. Somewhat beneficial
_____c. No impact
_____d. Somewhat detrimental
_____e. Very detrimental
_____f. Don't Know

29. Do you have any other comments about the functions and effect of such committees?

Permanent Loss of Consciousness: Expert Opinion and Community Standards

G

Expert Opinion*

This is in follow-up of our telephone conversation of December 18 in which you asked my informed opinion about prognosis in patients with so-called "permanent loss of consciousness" or what might be called the vegetative state.

As you know, there are only a limited number of published data on this subject. Included in the figures are some from Jennett's study of head injury, some from our own studies of nontraumatic coma, a series published from Japan, and a few reasonably well verified anecdotal reports. The results of all this material can be stated in the following manner:

1. Prognosis in permanently unconscious patients varies somewhat according to the nature of the underlying disease. In patients with traumatic brain damage, especially younger patients, a small number, perhaps 5%, can recover from such states lasting as long as 4-6 weeks. If complete unconsciousness lasts for longer than that period, I know of no evidence of a subject who has improved beyond the level of severe disability, and very few of the latter exist.

2. In ischemic brain injury, good recovery after a period of complete unconsciousness longer than two weeks is very rare, and longer than one month probably does not occur in more than a fraction of 1%. Even those few in whom late evidence of cognitive awareness has reappeared had to be classified as

* Letter from Dr. Fred Plum (Anne Parrish Titzell Professor of Neurology, Cornell University Medical College; Neurologist-in-Chief, The New York Hospital, New York, N.Y.) to Dr. Joanne Lynn regarding reliability of prognosis for permanently unconscious patients (Dec. 22, 1981).

having a severe disability both from the standpoint of physical and intellectual residua. I know of no example of such a patient who has returned to what can be considered independent intellectual or motor function. Wakefulness, of course, in the sense of having sleep and wake cycles, returns in almost all these subjects.

3. In conditions such as brain tumor, Alzheimer's disease, or other progressive dementias, loss of consciousness for a period lasting as long as one month dictates a hopeless prognosis. I suppose it is conceivable that such a patient could be overmedicated for a period of that duration, but I know of no example either by direct contact or anecdotal report of such a patient who has ever recovered any measure of cognition when all consciousness had been lost for a continuous period of 30 days or more.

In my experience, a major problem in this area lies with poor medical diagnosis. Many patients who are severely disoriented, agitated, or locked-in are sometimes called unconscious by physicians. The statements above, of course, can only apply when the diagnosis is secure.

If I can expand on these comments in any way, I will be pleased to. In the meantime, I hope this has been useful. Please call me if there are any questions.

Sincerely,
(signed)
Fred Plum, M.D.

Community Standards

Guidelines for Discontinuance of Cardiopulmonary Life-Support Systems under Specified Circumstances*

A. The general principles which should govern decision-making in this area are:

1. It is the right of a person capable of giving informed consent to make his or her own decision regarding medical care after having been fully informed about the benefits, risks and consequences of available treatment, even when such a decision might foreseeably result in shortening the individual's life.

2. Persons who are unable to give informed consent have the same rights as do persons who can give such consent. Decisions made on behalf of persons who cannot give their own informed consent should, to the extent possible, be the decisions which those persons would have made for themselves had they been able to do so. Parents (or the guardians) of a minor child, or the conservator of an adult patient, must consent to the decision. Family members of adult patients should always be consulted, although they have no legal standing under present California law to make such decisions on behalf of the patient.

3. A physician may discontinue use of a cardiopulmonary life-support system (i.e. mechanical respirator or ventilator), and is not required to continue its use indefinitely solely because such support was initiated at an earlier time.

4. The dignity of the individual must be preserved and necessary measures to assure comfort be maintained at all times.

5. It is the right of individual physicians to decline to participate in the withdrawal of life-support systems. In exercising this right, however, the physician must take appropriate steps to transfer the care of the patient to another qualified physician.

B. Three sets of circumstances in which decisions to discontinue the use of cardiopulmonary life-support systems can be made without the necessity of prior approval by the courts are:

1. **Brain death.** Section 7180 of the California Health and Safety Code states: "A person shall be pronounced dead if it is determined by a physician that the person has suffered a total and irreversible cessation of brain function." This statute also requires that a second physician independently confirm the

* Developed by the Joint Ad Hoc Committee on Biomedical Ethics of the Los Angeles County Medical Association and the Los Angeles County Bar Association

death and that neither physician be involved in decisions regarding transplantation of organs.

a. The physicians should document in the medical record the basis for the diagnosis of brain death.

b. The patient should be pronounced brain dead before disconnecting the respirator or ventilator.

c. It is desirable to explain the brain death law to family members and other interested persons before this procedure is implemented.

2. **California Natural Death Act.** Sections 7185 through 7195 of the California Health and Safety Code (the California Natural Death Act) provide that cardiopulmonary life-support systems must be withdrawn from patients who have signed a "valid and binding" Directive to Physicians. For further information, physicians should consult the Guidelines on the California Natural Death Act adopted by the California Medical Association and the California Hospital Association (CHA). These guidelines are reproduced in the CHA Consent Manual.

3. **Irreversible Coma*** Cardiopulmonary life-support systems may be discontinued if all of the following conditions are present:

a. The medical record contains a written diagnosis of irreversible coma, confirmed by a physician who by training or experience is qualified to assist in making such decisions. The medical record must include adequate medical evidence to support the diagnosis;

b. The medical record indicates that there has been no expressed intention on the part of the patient that life-support systems be initiated or maintained in such circumstances, and

c. The medical record indicates that the patient's family, or guardian or conservator, concurs in the decision to discontinue such support.

Adopted by the Council of the Los Angeles County Medical Association on March 2, 1981, and by the Board of Trustees of the Los Angeles Bar Association on March 11, 1981.

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* While paragraph B(1) and B(2), dealing with brain death and the California Natural Death Act, are based on provisions of the California Health and Safety Code, this paragraph, dealing with irreversible coma, is not based on any California statute or court decision, but rather reflects our view of good medical practice and the current standard of medical care in Los Angeles County.

New Jersey Guidelines for Health Care Facilities to Implement Procedures Concerning the Care of Comatose Non-Cognitive Patients*

In order to assist and guide the medical profession and the governing authorities of health care facilities† in the implementation of the procedures required by the New Jersey Supreme Court for cases similar to that of Karen Ann Quinlan, the formation and operation of the requisite Prognosis Committee is described herein. The term, Prognosis Committee, recognizes the Court's view that "the focal point of decision should be the prognosis as to the reasonable possibility of return to cognitive and sapient life."

The basic decision-making procedure, as paraphrased from the Court's conclusions, would be as follows:

> Upon the concurrence of the family, and in cases where required by law, the guardian†† of the patient, should the responsible attending physicians conclude that there is no reasonable possibility of the patient's ever emerging from a comatose condition to a cognitive, sapient state and that the life-support apparatus being administered to the patient should be discontinued, they shall consult with the Prognosis Committee (or like body) serving the institution in which the patient is confined.
>
> If that consultative body agrees that there is no reasonable possibility of the patient's ever emerging from a comatose condition to a cognitive, sapient state, the life-support system may be withdrawn and said action shall

---

* The Medical Society of New Jersey, the Association of Osteopathic Physicians and Surgeons, and the New Jersey Hospital Association (Jan. 26, 1977). Available from the New Jersey Dept. of Health, P.O. Box 1540, Trenton, N.J. 08625.

† In this context, "health care facility" means an institution or facility as defined in the Health Care Facilities Planning Act (N.J.S.A. 26:2H-2a).

†† The term guardian as here used refers to the "guardian of the person of the incompetent." This individual may be designated by a Court to make decisions for the incompetent concerning the incompetent's physical state and bodily integrity, such as the acceptance or refusal of various types of treatment. Such guardians are bound by traditional fiduciary duties, and must act in the perceived best interests of the incompetent.

This form of guardianship is contrasted with the "guardian of the property of the incompetent" who may be designated by a court to make decisions for the incompetent concerning dispositions of the incompetent's reality and personality. Such guardians have no control over the disposition of the incompetent's body, i.e., person, and are not involved in any decisions concerning the incompetent's medical treatment.

be without any civil or criminal liability therefor on the part of any participant, whether guardian, physician, hospital or others.

A Prognosis Committee, which will facilitate the decision-making process outlined by the Court, should be established or arranged for by those health care facilities which receive inpatients who are or may become comatose and non-cognitive. The Committee should function in the manner indicated by the following guidelines.

A. **Responsibility for Forming the Prognosis Committee**

The Board of Trustees, or responsible governing authority of the facility, shall have the responsibility to select those physicians who will form the Prognosis Committee. The physicians shall be designated to serve for a specified term and one of these physicians shall be selected by the governing authority to chair the Prognosis Committee.

B. **Composition of the Prognosis Committee**

1. A standard complement of medical disciplines shall be represented on the Prognosis Committee. These disciplines will be: General Surgery; Medicine; Neurosurgery or Neurology; Anesthesiology; and Pediatrics (if so indicated by the type of patient). At least two (2) additional physicians from any appropriate disciplines shall be selected from outside the staff of the facility to serve on the Prognosis Committee.

2. It is highly desirable that the physicians serving on the Prognosis Committee be Board Certified in their respective specialties.

3. At the time that the Prognosis Committee is required to consider a case, the family, guardian or attending physician can request that the Prognosis Committee consult with a specific physician named by any of them. The medical specialty of such physician should be predicated upon the particular characteristics of the patient's case. The Prognosis Committee shall accede to this request. The family may also designate a physician, other than the attending physician, to be present throughout the Committee's proceedings.

4. Under no circumstances should any of the physicians serving on the Prognosis Committee have been the attending or treating physician on the case under consideration.

NOTE: In order to proceed with the establishment of the requisite Prognosis Committees some facilities, because of staff limitations, may need assistance in this effort or may desire to act cooperatively with neighboring institutions. For example, the regionalizing (or sharing) of a Prognosis Committee to serve several health care facilities is recommended as a practical approach. It is suggested, therefore, that health care facilities seek assistance in developing and coordinating such arrangements from the New Jersey Hospital Association as

well as the professional medical organizations (The Medical Society of New Jersey, and the New Jersey Association of Osteopathic Physicians and Surgeons).

C. **Activation of the Prognosis Committee**

1. The patient's family or guardian, or the attending physician acting on behalf of the family may, in writing, request the health care facility's chief executive officer (administrator) to activate the Prognosis Committee to begin its work on a case. In the event that this request is made by the guardian of the patient, such individual shall present legal documentation so designating his status to the chief executive officer of the health care facility. The administrator has the responsibility to ensure that all of the required physician selections are made and to notify the Chairman of the Board of Trustees, or other responsible governing authority, as to the status of the Committee's composition.

2. The administrator shall advise the designated Chairman of the Prognosis Committee to have the group proceed promptly and with due diligence to come to a conclusion either supporting (concurring) or rejecting the prognosis of the attending physician.

3. The administrator shall also make readily available to the family the counselling and support services of the health care facility, or of the surrounding community.

D. **Prognosis Committee Functions and Reporting Requirements**

1. The Committee shall review all relevant patient records, with the family's consent, and shall seek additional medical information concerning the patient from those nursing personnel and other professionals it deems appropriate to the case under consideration. The Committee shall also determine which member or members will conduct a complete examination of the patient.

2. During the course of its deliberations, the Committee should arrive at a clear consensus with respect to the prognosis of the patient although the Supreme Court's decision does not expressly require unanimity. It is recognized that professional standards dictate caution in the determination of the prognosis.

3. The Chairman of the Prognosis Committee shall summarize and report the Committee's conclusion, in writing, to the chairman of the hospital's Board of Trustees, or other responsible governing authority, the attending physician, the administrator of the hospital, the patient's family, and when appropriate, the patient's guardian. The report shall consist of the Committee's findings concerning the prognosis of the patient, supplemented by a summary of the information considerd including professional consultations, if any, and the reasons supporting their conclusion. The report shall identify each of

the participating members of the Committee and their respective specialties and which member or members performed the complete examination of the patient. Finally, the Committee shall make a specific written finding in the report as to whether there is no reasonable possibility of the patient's ever emerging from a comatose condition to a cognitive, sapient state. The report shall be retained and preserved by the health care facility as part of the medical record of the patient.

E. **The Continuing Responsibility of the Attending Physician**

It should be recognized from the foregoing that the function and responsibility of the Prognosis Committee is limited to the application of specialized medical knowledge to a particular case in order to arrive at a determination of concurrence or non-concurrence with the prognosis of the attending physician. Once that determination has been made and reported, the Committee has thereby discharged its responsibility. The attending physician, guided by the Committee's decision and with the concurrence of the family, may then proceed with the appropriate course of action and, if indicated, shall personally withdraw life-support systems.

Seriously Ill Newborns: A Federal Directive and Sample State Statutes

H

Discriminating Against the Handicapped by Withholding Treatment or Nourishment*

There has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects. Reports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome.

This notice is intended to remind affected parties of the applicability of section 504 of the Rehabilitation Act of 1973 (29 U.S.C. 794). Section 504 provides that "No otherwise qualified handicapped individual...shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance...." Implementing regulations issued by the Department of Health and Human Services make clear that this statutory prohibition applies in the provision of health services (45 C.F.R. 84.52) and that conditions such as Down's syndrome are handicaps within the meaning of section 504 (45 C.F.R. 84.3(j)).

Under section 504 it is unlawful for a recipient of Federal financial assistance to withhold from a handicapped infant nutritional sustenance or medical or surgical treatment required to correct a life-threatening condition, if:

(1) the withholding is based on the fact that the infant is handicapped; and

* Notice to Health Care Providers (May 18, 1982), from the Office of the Secretary, Department of Health and Human Services, 47 Federal Register 26,027 (June 16, 1982).

(2) the handicap does not render the treatment or nutritional sustenance medically contraindicated.

For example, a recipient may not lawfully decline to treat an operable life-threatening condition in an infant, or refrain from feeding the infant, simply because the infant is believed to be mentally retarded.

We recognize that recipients of Federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent has been refused. Nevertheless, a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person or organization. 45 C.F.R. 84.4(b)(1)(v). Recipients must accordingly insure that they do not violate section 504 by facilitating discriminatory conduct.

In fulfilling its responsibilities, a Federally assisted health care provider should review its conduct in the following areas to insure that it is not engaging in or facilitating discriminatory practices:

- Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.
- Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.
- Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.

The failure of a recipient of Federal financial assistance to comply with the requirements of section 504 subjects that recipient to possible termination of Federal assistance. Moreover, section 504 does not limit the continued enforcement of State laws prohibiting the neglect of children, requiring medical treatment, or imposing similar responsibilities.

Betty Lou Dotson,
Director,
Office for Civil Rights

Nondiscrimination on the Basis of Handicap*

Summary: The interim final rule modifies existing regulations to meet the exigent needs that can arise when a handicapped infant is discriminatorily denied food or other medical care. Three current regulatory provisions are modified to allow timely reporting of violations, expeditious investigation, and immediate enforcement action when necessary to protect a handicapped infant whose life is endangered by discrimination in a program or activity receiving federal financial assistance.

Recipients that provide health care to infants will be required to post a conspicuous notice in locations that provide such care. The notice will describe the protections under federal law against discrimination toward the handicapped, and will provide a contact point in the Department of HHS for reporting violations immediately by telephone.

Notice and complaint procedures have been effective instruments for deterrence and enforcement in a variety of civil rights contexts. The Secretary believes that the interim final rule provides the best means to ensure that violations can be reported in time to save the lives of handicapped children who are denied food or are otherwise imperiled by discrimination in the provision of health care by federally assisted programs or activities.

The procedures to be followed for investigation of complaints are outlined in the supplementary information below. The Secretary intends to rely heavily on the voluntary cooperation of State and local agencies, which are closest to the scene of violations, and which have traditionally played the key role in the investigation of complaints of child abuse and neglect. This will not exclude, or course, a vigorous federal role in enforcing the federal civil rights that are at issue.

The Secretary invites comments on all aspects of the interim final rule. Aspects on which comment is particularly invited are set forth in the supplementary information.

Dates: The interim final rule becomes effective March 22, 1983. Comments should be submitted by May 6, 1983.

Addresses: Comments should be submitted in writing to the Director, Office for Civil Rights. Department of Health and Human Services, 330 Independence Avenue, S.W., Room 5400, Washington, D.C. 20201, or delivered to the above address between 9:00 a.m. and 5:30 p.m. on regular business days. Comments received may be inspected during these same hours by making arrangements with the contact person shown below.

*Notice of Interim Final Rule, Office of the Secretary, Department of Health and Human Services, 48 Federal Register 9630 (March 7, 1983).

For Further Information Contact: Susan Shalhoub at (202) 245-6585. Office for Civil Rights, Department of Health and Human Services, 330 Independence Avenue, S.W., Room 5514, Washington, D.C. 20201.

Supplementary Information: The President's directive of April 30, 1982, and the HHS Office for Civil Rights "Notice to Health Care Providers" of May 18, 1982, reminded recipients of federal financial assistance of the applicability of Section 504 of the Rehabilitation Act of 1973. Section 504 provides: "No otherwise qualified handicapped individual...shall, solely by reason of his handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance."

The Notice to Health Care Providers explained what is already clear from the language of Section 504 and the implementing regulations (45 CFR Part 84): The discriminatory failure of a federally assisted health care provider to feed a handicapped infant, or to provide medical treatment essential to correct a life-threatening condition, can constitute a violation of Section 504.

This interim final rule does not in any way change the substantive obligations of health care providers previously set forth in the statutory language of Section 504, in the implementing regulations, and in the Notice to Health Care Providers. The interim final rule sets forth procedural specifications designed (1) to specify a notice and complaint procedure, within the context of the existing regulations, and (2) to modify existing regulations to recognize the exigent circumstances that may exist when a handicapped infant is denied food or other necessary medical care.

The interim final rule affects the following portions of existing regulations:

1. **45 CFR 80.6(d)**, as referenced by 45 CFR 84.61, which requires recipients to make available such information, in such a manner, as the Department finds necessary to apprise appropriate persons of the protections afforded under Section 504. The interim final rule specifies the type of information and manner of posting that is necessary to bring the protections of Section 504 for handicapped infants to the attention of those persons within the recipient program or activity who are most likely to have knowledge of possible violations as they occur.

2. **45 CFR 80.8**, as referenced by 45 CFR 84.61, which sets forth procedures for the Secretary to effect compliance with Section 504, including referrals to the Department of Justice for the initiation of appropriate legal proceedings. The existing regulations require a 10-day waiting period from the time the Secretary notifies a recipient of its failure to comply to the time the Secretary makes a referral to the Department of Justice or takes other legal actions to effect compliance. When a

handicapped infant is being denied food or other necessary medical care, however, more expeditious action may be required. New Section 84.72 creates a narrow exception to the 10-day waiting period when, in the judgment of the responsible Department official, immediate remedial action is necessary to protect the life or health of a handicapped individual.

3. **45 CFR 80.6(c)**, as referenced by 45 CFR 84.61, which requires each recipient to permit access by Department officials to facilities and information pertinent to ascertaining compliance with Section 504, during normal business hours. Allegations of denial of food or other necessary medical care to handicapped infants may require an immediate effort to ascertain compliance. The interim final rule provides that access to records and facilities of recipients shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

The purpose of the interim final rule is to acquire timely information concerning violations of Section 504 that are directed against handicapped infants, and to **save the life of the infant**. The Secretary believes that those having knowledge of violations of Section 504 against handicapped infants do not now have adequate opportunity to give immediate notice to federal authorities. A telephone complaint procedure can provide information to federal authorities in time to save the life of a handicapped infant who is being discriminatorily denied nutrition in a federally assisted program or activity.

Events of the past several years suggest that handicapped infants have died from denial of food in federally assisted programs. The full extent of discriminatory and life-threatening practices toward handicapped infants is not yet known, but the Secretary believes that for even a single infant to die due to lack of an adequate notice and complaint procedure is unacceptable.

For quick and effective response to complaints, the Secretary counts not only the enforcement resources of the Federal government, but also on the assistance of state child protective agencies, which can respond quickly and effectively to referrals from the Federal government, and which are often closest to the scene for speedy investigation of life-threatening child abuse and neglect. The Secretary intends to contact state child protective agencies whenever a complaint is received that falls within the definition of child abuse or neglect, in order to give States an opportunity to make their own investigation and to take appropriate action.

The Secretary expects that States will follow their customary procedures for investigating allegations of child abuse and neglect that involve an imminent danger to life. State agencies that receive federal financial assistance are under the same

obligation as other recipients not to provide a qualified handicapped person with benefits or services that are less effective than those provided to others.

For those complaints that are expeditiously and effectively investigated and pursued by State agencies, the Secretary anticipates that additional federal efforts will often be unnecessary. The Secretary will closely monitor all investigation and enforcement activity taken pursuant to complaints. The Secretary will make available to State agencies any information and assistance that is helpful and appropriate. For those cases where direct federal action appears helpful, the Secretary will have at his disposal the usual means of federal civil rights enforcement. The interim final rules makes it possible for the Secretary to conduct immediate investigations and to make immediate referrals to the Department of Justice for such legal action as may be necessary to save the life of a handicapped child who is subjected to discrimination by a recipient.

Federal enforcement action can also be taken against any recipient that intimidates or retaliates against any person who provides information concerning possible violations of Section 504. 45 CFR 80.7(e), as referenced by 45 CFR 84.61, prohibits intimidatory or retaliatory acts by recipients against individuals who make complaints or assist in investigations concerning possible violations of Section 504. This provision fully protects individuals who make complaints or assist in investigations concerning possible withholding of food or other necessary medical care from handicapped infants.

Comments solicited. The Secretary seeks public comment on all aspects of the interim final rule. Comments will be considered and modifications made to the rule, as appropriate, following the comment period.

The Secretary also solicits comments on the advisability of requiring (1) that recipients providing health care services to infants perform a self-evaluation, pursuant to 45 CFR 84.6(c)(1), with respect to their policies and practices concerning services to handicapped infants; and (2) that such recipients identify for parents of handicapped children those public and private agencies in the geographical vicinity that provide services to handicapped infants.

Regulatory impact analysis. This Rule has been reviewed under Executive Order 12291. It is not a major rule and thus does not require a regulatory impact analysis.

Regulatory flexibility analysis. The Regulatory Flexibility Act (Pub. L. 96-354) requires the federal government to anticipate and reduce the impact of rules and paperwork requirements on small usinesses and other small entities. This Rule has no significant effect on small entities. Therefore, a regulatory flexibility analysis is not required.

Paperwork Reduction Act. This Rule contains no information collection requirements subject to the Paperwork Reduction Act of 1980 (Pub. L. 96-511).

Public participation in rulemaking. With reference to the Secretary's Statement of Policy, dated January 28, 1971, concerning public participation in rulemaking (printed at 36 FR 2532; Feb. 5, 1971), the Secretary finds that this interim final rule is exempt from the requirements of 5 U.S.C. 553. Under 45 CFR 80.6(d) and 84.61, the Secretary is already authorized to specify the manner in which recipients make available information concerning federal legal protections against discrimination toward the handicapped. The exception to the 10-day waiting period of 45 CFR 80.8(d)(3) and the exception to 45 CFR 80.6(c) to allow access outside normal business hours are minor technical changes and are necessary to meet emergency situations. All modifications made by the interim final rule are necessary to protect life from imminent harm. Any delay would leave lives at risk. Immediate publication and implementation of this rule will not cause undue burden to any party. The Secretary therefore finds it necessary to publish this rule as an interim final rule taking effect less than 30 days following publication. The Secretary deems 15 days to be the minimum in which the necessary apparatus can be in place to receive and respond to telephone complaints. The interim final rule is therefore made effective March 22, 1983.

Approved: March 2, 1983

Thomas R. Donnelly, Jr., Acting Secretary

Part 84—[Amended]

Interim Final Rule

45 CFR 84.61 is amended by designating the existing provision as paragraph (a) and by adding paragraphs [b], [c], and [d] to read as follows:

§ 84.61 [Amended]

(b) Pursuant to 45 CFR 80.6(d), each recipient that provides covered health care services to infants shall post and keep posted in a conspicuous place in each delivery ward, each maternity ward, each pediatric ward, and each nursery, including each intensive care nursery, the following notice:

DISCRIMINATORY FAILURE TO FEED AND CARE FOR HANDICAPPED INFANTS
IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW

Section 504 of the Rehabilitation Act of 1973 states that no otherwise qualified handicapped individual shall, solely by reason of handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.

Any person having knowledge that a handicapped infant is being discriminatorily denied food or customary medical care should immediately contact:

Handicapped Infant Hotline
U.S. Department of Health and Human Services
Washington, D.C. 20201
Phone 800-_____ (Available 24 hours a day)

or

Your State Child Protective Agency

Federal law prohibits retaliation or intimidation against any person who provides information about possible violations of the Rehabilitation Act of 1973.

Identity of callers will be held confidential.

Failure to feed and care for infants may also violate the criminal and civil laws of your State.

(1) Recipients may add to the notice, in type face or handwriting, under the words "Your State Child Protective Agency," the identification of an appropriate State agency, with address and telephone number. No other alterations shall be made to such notice.

(2) Copies of such notice may be obtained on request from the Department of Health and Human Services.

(3) The required notice shall be posted within five days after the recipient is informed by the Department of the applicable toll-free national telephone number.

(c) Notwithstanding the provisions of paragraph (a), the requirement of 45 CFR 80.8(d)(3) shall not apply when, in the judgment of the responsible Department official, immediate remedial action is necessary to protect the life or health of a handicapped individual.

(d) Notwithstanding the provisions of paragraph (a), access to pertinent records and facilities of a recipient pursuant to 45 CFR 80.6(c) shall not be limited to normal business hours when, in the judgment of the responsible Department official, immediate access is necessary to protect the life or health of a handicapped individual.

1982 Louisiana Act regarding nutrition and medical care of children*

To enact Part XIX of Chapter 5 of Title 40 of the Louisiana Revised

Statutes of 1950, to be comprised of R.S. 40:1299.36.1 through R.S. 40:1299.36.3, relative to nutritional or medical deprivation of infants, to provide with respect to infants denied or deprived of food, water or medical care with the intent to cause or allow the death of the child, to provide for procedures when parental consent for necessary care and treatment is refused, to provide with respect to judicial proceedings to enforce the provisions of this Part, and otherwise to provide with respect thereto.

Be it enacted by the Legislature of Louisiana:

Section 1. Part XIX of Chapter 5 of Title 40 of the Louisiana Revised Statutes of 1950, comprised of R.S. 40:1299.36.1 through R.S. 40:1299.36.3, is hereby enacted as follows:

PART XIX. PRESERVING THE LIFE OF CHILDREN

§ 1299.36.1. Infants born alive and other children; nutritional and medical deprivation prohibited.

A. No infant born alive shall be denied or deprived of food or nutrients, water, or oxygen by any person whomsoever with the intent to cause or allow the death of the child for any reason, including but not limited to the following:

(1) The child was born with physical or mental handicapping conditions which, in the opinion of the parent or parents of the child, the physician, or other persons, diminishes the quality of the child's life.

(2) The child is not wanted by the parent.

(3) The child is born alive in the course of an attempted abortion.

No infant child shall be intentionally killed by any other means by any person for any reason.

B. No minor child, from the moment of live birth, shall be intentionally denied or deprived of any medical or surgical care by his or her parent, physician, or any other person when such medical or surgical care is necessary to attempt to save the life of the child, in the opinion of a physician exercising competent medical judgment, despite the opinion of the child's parent or parents, the physician, or others that the quality of the child's life would be deficient should the child live.

*Enacted Sept. 10, 1982.

C. Nothing in this Section shall be interpreted to prevent a child's parents and physician from discontinuing the use of life support systems or other medical treatment for a child in a continual profound comatose state where, in the opinion of the child's physician exercising competent medical judgment, the child has no reasonable chance of recovery from said comatose state despite every appropriate medical treatment to correct such condition.

D. This Section shall not be interpreted to require the provision of potentially lifesaving medical or surgical care to a child when in the opinion of the child's parent or parents and their physician exercising competent medical judgment, the potential risks to the child's life or health inherent in the treatment or surgery itself outweigh the potential benefits for survival from the treatment of surgery itself.

E. No child who is being provided treatment in accordance with the tenets of a well-recognized religious method of healing in lieu of medical treatment shall for that reason alone be considered to be neglected under the provisions of this Part, unless the life of the child is substantially and seriously threatened due to the lack of traditional medical care. Provided however that the parents of a child whose life the department alleges is substantially and seriously threatened due to lack of traditional medical or surgical care shall have the right to petition a district court of competent jurisdiction for a temporary restraining order or injunction prohibiting the Department from intervening in the matter. The court shall give preference to such hearings, and such matters shall be tried summarily.

§ 1299.36.2. Parental consent to care and treatment; refusal.

A. Whenever the parent or parents of a child refuse to consent to the care and treatment of the child protected by R.S. 40:1299.36.1, they shall at all times be free to execute a voluntary act of surrender of the child pursuant to R.S. 9:402, placing the child in the custody of the Department of Health and Human Resources or other licensed adoption agency. All medical expenses incurred by the Department of Health and Human Resources on behalf of the child shall be reimbursed by the parent or parents of the child, provided they have not been declared financially needy. No medical insurer of the parent or parents of a child who would have otherwise been liable for such medical expenses may deny liability to their insured solely because of the parent or parents desire to withhold medical or surgical treatment from the child. The agency shall immediately provide the treatment for the child and shall make every effort to find an adoptive home for the child.

B. Whenever the parent of a child protected by R.S. 40:1299.36.1 refuses to consent to the necessary care and treatment for the child, but refuses to surrender the child for adoption, the physician, or other persons included in the

provisions of R.S. 14:403 shall report the child as a neglected child or child in need of care to the local child protection agency or to the police.

C. No physician, hospital, or other person authorized by law to provide medical or surgical care shall be held liable for providing medical or surgical care for a child protected by R.S. 40:1299.36.1 without the consent of the child's parent or the agency having custody of the child, when in the opinion of the physician, hospital, or other person authorized by law to provide medical or surgical care, exercising competent medical judgment, the child's life would be threatened by delaying the provision of the care or treatment.

§ 1299.36.3. Judical proceedings.

A. Judicial proceedings to enforce the provisions of this Part may by instituted by any agency, institution, or person interested in the child's welfare in the juvenile court in the jurisdiction where the child is found. All such proceedings shall be heard in confidence without delay, including the holding of special sessions of court. Any appeal or application for writs in any appellate court in cases arising from this Section shall be heard and decided in the shortest possible time. An attorney shall be appointed to represent the child in all trial and appellate proceedings.

B. Nothing in this Part shall diminish the application of the Louisiana Criminal Code where appropriate.

Section 2. If any provision or item of this Act or the application thereof is held invalid, such invalidity shall not affect other provisions, items, or applications of this Act which can be given effect without the invalid provisions, items, or applications, and to this end the provisions of this Act are hereby declared severable.

Section 3. All laws or parts of laws in conflict herewith are hereby repealed.

Model Child Protection Act*

§ 1. Title.

This Act shall be known as the Child Protection Act of 19_____.

§ 2. Findings and purpose.

Abused and neglected children in this state urgently need protection. It is the purpose of this Act to help protect them from further injury and harm. This Act seeks to establish an effective state and local system for child protection by providing those procedures necessary to safeguard the well-being and development of endangered children and to preserve and stabilize family life, whenever appropriate. Recognizing that children also can be abused and neglected while living in public and private residential facilities and institutions meant to serve them, this Act also provides for handling of reports of abuse and neglect of children in residential institutions.

§ 3. Persons or families needing assistance encouraged to seek it.

Any person or family seeking assistance in meeting child care responsibilities may use, and is encouraged to use, the services and facilities established by this Act. Such persons or families shall be referred to appropriate community resources or agencies regardless of whether or not the problem presented constitutes child abuse or neglect as defined by this Act. No person seeking assistance under this section shall be required to give his name or any other identifying information.

§ 4. Definitions.

When used in this Act and unless the specific context indicates otherwise:

(a) "Child" means a person under the age of 18.

(b) An "abused or neglected child" means a child whose physical health is harmed or threatened with harm by the acts or omissions of his parent or other person responsible for his welfare, or whose mental health is harmed or threatened with harm.

(c) "Harm" to a child's health or welfare occurs when the parent or other person responsible for welfare:

(i) inflicts, or allows to be inflicted, upon the child, physical or mental injury, including injuries sustained as a result of excessive corporal punishment; or

(ii) commits, or allows to be committed, a sexual act with a child; or

*National Center on Child Abuse and Neglect, U.S. Dept. of Health and Human Services, CHILD PROTECTION: A GUIDE FOR STATE LEGISLATION, U.S. Government Printing Office, Washington, D.C. (1983) at 43.

(iii) allows, encourages, or forces a child to solicit for or engage in prostitution; or engage in the filming, photographing, videotaping, posing, modeling, or performing before a live audience, where such acts involve exhibition of the child's genitals or any sexual act with the child; or

(iv) fails to meet the following needs of the child though financially able to do so or offered financial or other reasonable means to do so:

- such food, clothing, or shelter necessary for the child's health or safety
- education as defined by state law
- adequate health care (adequate health care includes any medical or nonmedical remedial health care permitted or authorized under state law); or

(v) abandons the child, as defined by state law; or

(vi) fails to provide the child with adequate care or supervision necessary for the child's health or safety; or leaves the child unattended over a period of time causing a risk of harm to the child's health or safety.

(d) "Allows to be inflicted" or "allows to be committed" means that the parent or other person responsible for the child's welfare knows or has reasonable cause to suspect that the child has been harmed and did nothing to prevent or stop it.

(e) "Sexual act" means:

(i) any penetration, however slight, of the vagina or anal opening of one person by the penis of another person, whether or not there is the emission of semen; or

(ii) any sexual contact between the genitals or anal opening of one person and the mouth or tongue of another person; or

(iii) any intrusion by one person into the genitals or anal opening of another person, including the use of any object for this purpose, EXCEPT that, it shall not include acts intended for a valid medical purpose; or

(iv) the intentional touching of the genitals or intimate parts (including the breasts, genital area, groin, inner thighs, and buttocks) or the clothing covering them, of either the child or the perpetrator, EXCEPT that, it shall not include acts which may reasonably be construed to be normal caretaker responsibilities, interactions with, or affection for a child or acts intended for a valid medical purpose, or

(v) the masturbation of the perpetrator's genitals in the presence of a child, or

(vi) the intentional exposure of the perpetrator's genitals in the presence of a child, if such exposure is for the purpose of sexual arousal or gratification, aggression, degradation, or other similar purpose; or

(vii) any other sexual act, intentionally perpetrated in the presence of a child, for the purpose of sexual arousal or gratification, aggression, degradation, or other similar purpose.

(f) "Threatened harm" means a substantial risk of immediate harm.

(g) "A person responsible for a child's welfare" includes the child's parent; guardian; foster parent; stepparent with whom the child lives; an employee of a public or private residential home, institution or agency; or other person legally responsible for the child's welfare in a residential setting.

(h) "Physical injury" means death, or permanent or temporary disfigurement or impairment of any bodily organ or function.

(i) "Mental injury" means an injury to the intellectual or psychological capacity of a child as evidenced by an observable and substantial impairment in his ability to function within his normal range of performance and behavior, with due regard to his culture.

(j) "Institutional child abuse and neglect" means situations of known or suspected child abuse or neglect where the person responsible for the child's welfare is a foster parent or the employee or volunteer of a public or private residential care facility, institution, or agency providing around-the-clock care for children.

(k) "State department" means the department designated under section 14 to have prime responsibility for state efforts to strengthen and improve the prevention, identification, and treatment of child abuse and neglect.

(l) "Local agency" means the agency designated under Section 14 to have prime responsibility for providing local child protective services.

(m) "Child protective services" is a specialized child welfare service responsible for the receipt and investigation of reported instances of child abuse and neglect and providing or arranging for needed services in confirmed cases.

(n) "Subject of the report" means any person reported under this Act, including any child or parent, guardian, or other person responsible for the child's welfare.

(o) "Unfounded report" means a report made pursuant to this Act for which there is no reasonable cause to believe that the child is abused or neglected. For the purposes of this Act, it is presumed that all reports are unfounded unless the child protective service determines otherwise.

(p) "Reasonable cause to believe" means facts and circumstances based upon accurate and reliable information that would justify a reasonable person to believe that a child subject to a report under this Act is abused or neglected. Such facts and circumstances may include evidence of an injury or

injuries, if not satisfactorily explained, and the statements of a person worthy of belief, even if there is no present evidence of injury.

(q) "Reasonable cause to suspect" means facts and circumstances based upon accurate and reliable information that would justify a reasonable person to suspect.

(r) "Excessive corporal punishment" means reckless, unjustifiable, unduly severe, or disproportionate punishment or disciplinary measures which cause, or create a substantial risk of causing, disfigurement, impairment of bodily functioning, or other serious physical or mental injury.

(s) As used in this Act, words of the masculine gender include the feminine.

§ 5. Persons and officials required to report known and suspected child abuse or neglect.

(a) When the following professionals and officials know or have reasonable cause to suspect that a child known to them in their professional or offical capacity is an abused or neglected child, they are required to report or cause a report to be made in accordance with this Act: any physician; resident; intern; hospital personnel engaged in the admission, examination, care or treatment of persons; nurse; osteopath; chiropractor; podiatrist; medical examiner or coroner; dentist; optometrist; or any other health or mental health professional; Christian Science practitioner; religious healer; school teacher or other school official or pupil personnel; social worker; day care center staff or any other professional child care workers, foster care providers, residential or institutional worker; or peace officer or other law enforcement official.

(b) Whenever a person is required to report under this Act in his capacity as a member of the staff of a medical or other public or private institution, school, facility, or agency, he shall immediately notify the person in charge, or his designated agent, who shall then become responsible to make the report or cause the report to be made. However, nothing in this section or Act is intended to relieve individuals of their obligation to report on their own behalf, unless a report already has been made or will be made forthwith.

(c) Persons reporting instances of child abuse and neglect occurring in public or private residential institutions shall be immune from any adverse action with respect to employment by or in such institution arising out of such reporting.

§ 6. Any person permitted to report.

Any person may make a report under this Act, if he knows or has reasonable cause to suspect that a child is abused or neglected.

§ 7. Mandatory reporting of deaths to and postmortem investigation by medical examiner or coroner.

Any person or official required to report under this Act who has reasonable cause to suspect that a child has died as a result of child abuse or neglect shall report his suspicion to the appropriate medical examiner or coroner and any other person may do so as well. The medical examiner or coroner shall investigate the report and submit his findings, in writing, to the local law enforcement agency, the appropriate district attorney, the local child protective service, and, if the institution making the report is a hospital, the hospital.

§ 8. Photographs and x-rays.

Any person or official required to report or to conduct an investigation under this Act may take, or cause to be taken, photographs of the areas of trauma visible on a child who is the subject of a report and, if indicated by medical consultation, cause to be performed a radiological examination of the child without the consent of the child's parents or guardians. Whenever such person is required to report in his capacity as a member of the staff of a medical or other public or private institution, school, facility, or agency, he shall immediately notify the person in charge, or his designated agent, who shall then take or cause to be taken color photographs of visible trauma and shall, if indicated by medical consultation, cause to be performed a radiological examination of the child. The reasonable cost of photographs or x-rays taken under this section shall be reimbursed by the appropriate local child protective service. All photographs and x-rays taken, or copies of them, shall be sent to the local child protective service at the time the written confirmation report is sent, or as soon thereafter as possible.

§ 9. Protective custody.

(a) A police or law enforcement official [, *a designated worker of a child protective service*,]† and a physician treating a child may take a child into protective custody without the consent of parents, guardians, or others exercising temporary or permanent control over the child when he has reasonable cause to believe that (1) there exists an imminent danger to the child's life or safety, (2) the parents are unavailable or have been asked and do not consent to the child's removal from their custody, and (3) there is not time to apply for a court order.

(b) In the event there is not time to seek a court order the person in charge of any hospital or similar medical institution may retain custody of a child reasonably suspected of being abused or neglected, when he believes the facts so warrant, whether or not additional medical treatment is required and

†Optional; *see* Comment.

whether or not the parents or other person responsible for the child's welfare request the child's return.

(c) The child shall be taken immediately to a place previously designated for this purpose by the juvenile court or the local agency. Such place may include a foster home; group home; shelter; hospital, if the child is or will be admitted to the hospital; or other institution; but it shall not be a jail or other place for the detention, incarceration, or residential care of criminal offenders or juveniles either alleged or adjudicated as delinquents or status offenders.

(d) No child shall be kept in protective custody under this Act for more than twenty-four hours unless authorized by a judge of a court of record. If after 24 hours there has been no protective custody order from the court, the person having custody of the child shall return the child to his parents.

(e) Any person taking a child into protective custody shall immediately notify the appropriate local child protective service. Upon such notification, the service shall immediately see to the protection of any other children in the home, commence a child protective investigation in accordance with Section 13 of this Act, and make every reasonable effort to inform the parent or other person responsible for the child's welfare as to where the child has been taken. Parents shall be informed of where and when the case will be heard; their right to legal representation as well as the provision of legal representation if indigent; and their visitation rights. The service shall make a reasonable attempt to return the child to his home, whenever it seems safe to do so. At the next regular session of the juvenile court [or family court or similar civil court],* the service shall (i) commence a child protection proceeding in the court, or (ii) recommend to the court [court intake service or other initiating authority]** that one not be commenced. The court may order commencement of a proceeding even if the service recommends against doing so, if it finds that such a proceeding would be in the best interests of the child. If a proceeding is commenced, the service shall recommend whether or not the child should be returned to his parents or other person responsible for his welfare pending further court action.

§ 10. Immunity from liability.

Any person, official, or institution participating in good faith in any act authorized or required by this Act shall be immune from any civil or criminal liability which might otherwise result by reason of such action. Any person reporting under the provisions of the Act shall have a civil cause of

*As appropriate.
**Optional.

action against any person who causes a detrimental change in the employment status of the reporter by reason of the report.

§ 11. Abrogation of privileges.

The marital privilege, including the privilege against adverse testimony and the privilege against disclosure of confidential communications, and the privileged quality of communications between any professional person and his patient or client, and cannons of professional ethics, shall not apply, except that between attorney and client, to instances of known or suspected child abuse or neglect and shall not constitute grounds for failure to report as required or permitted by this Act. This privilege will not apply to cooperation with the child protective service in its activities pursuant to this Act, or to provision of evidence in any civil or criminal proceeding relating to child abuse or neglect.

§ 12. Penalties for failure to report or act.

Any person, official or institution required by this Act to report known or suspected child abuse or neglect, or required to perform any other act, who knowingly and willfully fails to do so or who knowingly and willfully prevents another person acting reasonably from doing so shall be guilty of a misdemeanor and shall be civilly liable for the damages proximately caused by such failure or prevention.

§ 13. Legal responsibilities of local agency.

(a) The local agency shall be capable of receiving reports of known or suspected child abuse or neglect twenty-four hours a day, seven days a week. If it appears that the immediate safety or well-being of a child is endangered, the family may flee or the child disappear, or the facts otherwise so warrant, the agency shall commence an investigation immediately, regardless of the time of day or night. In all other cases, a child protective investigation shall be commenced within twenty-four hours of receipt of the report. To fulfill the requirements of this section, the local agency shall have the capability of providing or arranging for comprehensive emergency services to children and families at all times of the day or night.

(b) For each report it receives, the local agency shall perform a child protective investigation within the time limits specified in (a) to: (i) determine the composition of the family or household, including the name, address, age, sex, and race of each child named in the report, and any siblings or other children in the same household or in the care of the same adults, the parents or other persons responsible for their welfare, and any other adults in the same household; (ii) determine whether there is reasonable cause to believe that any child in the family or household is abused or neglected, including a determination of harm or threatened harm to each child, the nature and extent of present or prior injuries, abuse

or neglect, and any evidence thereof, and a determination of the person or persons apparently responsible for the abuse or neglect; (iii) provided that there is probable cause determine the immediate and long-term risk if each child were to remain in the existing home environment; and (iv) determine the protective, treatment, and ameliorative services that appear necessary to help prevent further child abuse or neglect and to improve the home environment and the parents' ability to care adequately for the children. The purpose of the child protective investigation shall be to provide immediate and long term protective services to prevent further abuse or neglect and to provide, or arrange for, and coordinate and monitor treatment and ameliorative services necessary to safeguard and insure the child's well-being and development and, if possible, to preserve and stabilize family life.

(c) The local agency may waive a full child protective investigation of reports made by agencies or individuals if, after an appropriate assessment of the situation, it is satisfied that: (i) the protective and service needs of the child and the family can be met by the agency or individual, (ii) the agency or individual agrees to attempt to do so, and (iii) suitable safeguards are established and observed. Suitable safeguards shall include a written agreement from the agency or individual to report periodically on the status of the family, a written agreement to report immediately to the local agency at any time that the child's safety or well-being is threatened despite the agency's or individual's efforts, and periodic monitoring of the agency's or individual's efforts by the local service for a reasonable period of time.

(d) The local agency shall convene one or more interdisciplinary "Child Protection Teams" to assist it in its diagnostic, assessment, service, and coordination responsibilities. The head of the local agency or his designee shall serve as the team's coordinator. Members of the team shall serve at the coordinator's invitation and shall include representatives of appropriate health, mental health, social service, and law enforcement agencies.

(e) If the local child protective service is denied reasonable access to a child by the parents or other persons and the local service deems that the best interests of the child so require, it shall seek an appropriate court order or other legal authority to examine and interview such child.

(f) The child protective service may determine that a child requires immediate or long term protection, either through (1) medical or other health care, or (2) homemaker care, day care, casework supervision, or other services to stabilize the home environment, or (3) foster care, shelter care, other substitute care to remove the child from his parent's custody. If such a determination is made, services first shall be offered for the

voluntary acceptance of the parent or other person responsible for the child's welfare. If such services are refused and the child protective service deems that the child is in imminent danger the service shall seek an appropriate court order or other legal authority to protect the child.*

(g) After providing for the immediate protection of the child but prior to offering any services to a family, the local agency shall forthwith notify the adult subjects of the report and any other persons alleged to be responsible for the child abuse or neglect, in writing, of the existence of the report and their rights pursuant to this Act. This notification shall include an explanation of their right to refuse services and their right to obtain access to and amend, expunge, or remove reports in the central register of child protection cases. The local agency shall explain that it has no legal authority to compel the family to accept services; however, it shall inform the family of the obligations and authority of the local agency to petition the juvenile court to decide whether a child is in need of care and protection or to refer the case to the police or the district attorney who will then decide whether there shall be a criminal prosecution. Upon the initiation of any judicial action the parents shall be informed of their legal rights.

(h) If the local child protective service determines that there is not reasonable cause to believe that a child is abused or neglected, it shall close its protective case. However, if it appears that the child or family could benefit from other social services, the local service may suggest such services for the family's voluntary acceptance or refusal. If the family declines such services, the local service shall take no further action.

(i) If the local child protective service determines that there is reasonable cause to believe that a child is abused or neglected, based upon its determination of the protective, treatment, and ameliorative service needs of the child and family, the local service shall develop, with the family, an appropriate service plan for the family's voluntary acceptance or refusal. The local service shall comply with subsection (g) by explaining its lack of legal authority to compel the acceptance of services and shall explain its concomitant authority to petition the juvenile court or refer the case to the police, district attorney, or criminal court.

(j) If the local agency determines that the best interests of a child require juvenile court or criminal court action because the child is in need of protection, the local service may initiate a court proceeding or a referral to the appropriate court related service, police department, district attorney, or any combination thereof.

*The police and, if authorized by the optional provision in section 9(a), the child protective service may take the child into protective custody.

(k) The child protective service shall give telephone notice and immediately forward a copy of reports which involve the death of a child to the appropriate district attorney [or *other appropriate law enforcement agency*] and medical examiner or coroner. In addition, upon the prior written request of the district attorney of if the local service otherwise deems it appropriate, a copy of any or all reports made pursuant to this Act which allege criminal conduct shall be forwarded immediately by the child protective service to the appropriate district attorney.

(l) If a law enforcement investigation is also contemplated or is in progress, the child protective service shall coordinate their efforts and concerns with those of the law enforcement agency.

(m) In any juvenile or criminal court proceeding commenced by the child protective service or by any other individual or agency, the service shall assist the court during all stages of the court proceeeding, in accordance with the purposes of this Act, the juvenile court act, and the penal law.

(n) The child protective service may request and shall receive from any agency of the state, or any of its political subdivisions such cooperation, assistance, and information as will enable it to fulfill its responsibilities under this section.

§ 14. Designation of state department.

The state department responsible for the supervision or administration of the local agency and having prime responsibility for state efforts to strengthen and improve the prevention, identification, and treatment of child abuse and neglect shall be the State Department of _____.

§ 15. Powers, functions, and duties of the state department.

(a) The state department shall serve as a state clearinghouse on programs and groups providing or concerned with human services related to the prevention, identification, or treatment of child abuse or neglect. It shall compile, publish, and disseminate public, professional, and staff educational and training materials and provide training and technical assistance, directly or indirectly to personnel and agencies who are engaged or intend to engage in the prevention, identification and treatment of child abuse and neglect. The department shall encourage the development of improved and additional state and local programs and activities; encourage the assumption of prevention and treatment responsibilities by additional agencies and groups; encourage the coordination of existing programs and activities; and conduct, support, or foster research into the causes of child abuse and neglect and into the prevention, identification and treatment of child maltreatment.

(b) The state department shall establish a "statewide child protection office." The office shall be a separate organizational unit, singly administered and supervised within the

state department, with sufficient staff of acceptable qualifications and adequate resources, including telephone facilities, to fulfill the purposes and functions assigned to it by this Act, other laws, or administrative procedures.

§ 16. The information system (central register).

(a) There shall be a system statewide, for receipt of suspected reports of child maltreatment from persons, whether or not mandated by law, at any hour of the day or night, on any day of the week. Immediately upon receipt of such reports, the contents of the report shall be forwarded either orally or electronically to the appropriate local child protective agency. Any person or family seeking assistance in meeting child care responsibilities may also use this system to obtain assistance or information in accordance with section 3 of this Act. Any other person may use this system to obtain assistance or information concerning the handling of child protection cases.

(b) There shall be a central register of child protection cases maintained in the statewide office. Through the recording of appropriate information, the central register shall be operated in such a manner as to enable the office to evaluate regularly the effectiveness of the child protection system.

(c) The centralized information system (central register) shall perform the following functions:

(i) Maintain information on all reports of suspected child abuse and neglect received by the system in the state.

(ii) Reflect the results of the investigations of all reports of suspected child abuse and neglect received.

(iii) Reflect the management of all cases of child abuse and neglect.

(iv) Produce statistical information reflecting the operation of the child protection system in the state in a timely fashion.

(v) Contain such other information which the department determines to be in furtherance of the purposes of this Act.

(d) All information identifying the subjects of an unfounded report shall be expunged, forthwith. Identifying information on all other records shall be removed from the system no later than five years after the case is closed. However, if another report is received involving the same child, his sibling or offspring, or a child in the care of the same adults, the identifying information may be maintained in the register until five years after the subsequent case or report is closed.

(e) At any time, the information in the system may be amended, expunged, or removed upon good cause shown and upon notice to the subjects of the report and the local child protective service.

(f) Upon request, a subject of a report shall be entitled to receive a copy of all information contained in the system

pertaining to his case. However, there is authority to prohibit the release of data that would identify or locate a person who, in good faith, made a report or cooperated in a subsequent investigation, when it reasonably finds that disclosure of such inforamtion would be likely to endanger the life or safety of such person.

(g) At any time subsequent to the completion of the local child protective service investigation, a subject of a report may make a request to amend, expunge identifying information from, or remove the record of the report from the system. If the request is refused or there is a failure to act within thirty days, the subject shall have the right to a fair hearing to determine whether the record of the report should be amended, expunged, or removed on the grounds that it is inaccurate or it is being maintained in a manner inconsistent with this Act.

Such fair hearing shall be held within a reasonable time after the subject's request and at a reasonable place and hour. The appropriate local child protective service shall be given notice of the hearing. In such hearings, the burden of proving the accuracy and consistency of the record shall be on the state department and the appropriate local child protective service. A juvenile court [*family court or similar civil court*] finding of child abuse or child neglect shall be presumptive evidence that the report was not unfounded. The hearing shall be conducted by the head of the state department or his designated agent, who is hereby authorized and empowered to order the amendment, expunction, or removal of the record to make it accurate or consistent with the requirements of this Act. A decision on the request shall be made, in writing, at the close of the hearing, or within thirty days thereof, and shall state the reasons upon which it is based. Decisions of the state department under this section shall be subject to judicial review in the form and manner prescribed by the state civil procedure law.

(h) To the fullest extent possible, written notice of any amendment, expunction, or removal of any record made pursuant to this Act shall be served upon each subject of such report and the appropriate local child protective service. The service, upon receipt of such notice, shall take similar action in regard to the local child abuse and neglect records and shall inform, for the same purpose, any other individuals or agencies which received such record pursuant to this Act or in any other manner. Nothing in this section is intended to require the destruction of case records.

§ 17. Reports of institutional child abuse and neglect.

(a) The Governor shall designate in writing the public or private agency department or office or agencies responsible for investigating reports involving institutional child abuse or neglect. The designated agency or agencies must be other than

and separately administered from the one involved in the alleged acts or omissions. Subject to the preceding limitation, this may be the state department, the local child protective service, a law enforcement agency, or another appropriate agency.

(b) The designation by the Governor shall describe the specific terms and conditions of the designation, including the manner in which reports of known or suspected institutional child abuse or neglect, will be received and investigated, the remedial action which will be taken, and the manner in which the Governor will be kept fully informed of the progress, findings, and disposition of the investigation.

(c) To fulfill the purposes of this section, the state may purchase the services of the agency designated to investigate reports of known or suspected institutional child abuse or neglect.

§ 18. Confidentiality of reports and records.

(a) In order to protect the rights of the child, his parents, or guardians, all records concerning reports of child abuse and neglect, including reports made to the state department, state center, state central register, local child protective services, and all records generated as a result of such reports, shall be confidential and shall not be disclosed except as specifically authorized by this Act or other applicable law. It shall be a misdemeanor to permit, assist, or encourage the unauthorized release of any information contained in such reports or records.

(b) No person, official, or agency shall have access to such records unless in furtherance of purposes directly connected with the administration of this Act. Such persons, officials, agencies, and purposes for access include:

(i) a local child protective service in the furtherance of its responsibilities under this Act;

(ii) a police or law enforcement agency investigating a report of known or suspected child abuse or neglect;

(iii) the agency (agencies) or organizations (including its designated multidisciplinary case consultation team) legally mandated by any state law to receive and investigate reports of known and suspected child abuse and neglect;

(iv) a person legally authorized to place a child in protective custody when such person requires the information in the report or record to determine whether to place the child in protective custody;

(v) an agency with legal responsibility or authorization to care for, treat, or supervise a child or a parent, guardian, or other person responsible for the child's welfare who is the subject of a report;

(vi) any subject of the report or his attorney; if the subject of the report is a minor or is otherwise legally incompetent, the guardian of the person or his guardian *ad litem*;

(vii) a court, when access to such records may be necessary for the determination of an issue before such court; however, such access shall be limited to *in camera* inspection, unless the court determines that public disclosure of the information contained therein is necessary for the resolution of an issue then pending before it;

(viii) a grand jury, upon its determination that access to such records is necessary in the conduct of its official business;

(ix) any appropriate state or local official responsible for administration, supervision, or legislation in relation to the prevention or treatment of child abuse or neglect when carrying out his official functions;

(x) any person engaged in *bona fide* research or audit purposes; provided, however, that no information identifying the subjects of the report shall be made available to the researcher unless it is absolutely essential to the research purpose, suitable provision is made to maintain the confidentiality of the data, and the head of the state department or local agency gives prior written approval. The head of the state department shall establish, by regulation, criteria for application of this subdivision.

(c) upon written request, any person making a report shall be entitled to learn the general disposition of such report.

(d) A person given access to the names or other information identifying the subjects of the report, except the subject of the report, shall not make public such identifying information unless he is a district attorney or other law enforcement official and the purpose is to initiate court action. Violation of this subsection shall be a misdemeanor.

(e) Nothing in this Act is intended to affect existing policies or procedures concerning the status of court and criminal justice system records.

§ 19. Right to representation in court proceedings.

(a) Any child who is alleged to be abused or neglected in a juvenile court (family or other similar civil court) proceeding shall have independent legal representation in all proceedings arising from such allegations, including temporary custody or shelter hearings, adjudication, disposition, reviews, and termination of parental rights. The court shall appoint legal counsel to represent the child in such proceedings at public expense. The attorney representing the child under this section shall also serve as the child's guardian *ad litem* unless one has been appointed by the appropriate court. If, however, the attorney deems that, in a particular case, he cannot perform in this dual

capacity, he shall request that the court appoint a separate guardian *ad litem*.

(b) In a civil proceeding, any parent or other person responsible for a child's welfare alleged to have abused or neglected a child shall be entitled to legal representation in such proceeding, including shelter and custody hearings, adjudication, disposition, reviews and termination of parental rights actions. Such person shall also be entitled to legal representation in any criminal proceeding, including any appeals, arising from such allegations. Those individuals unable to afford private legal representation are to be appointed counsel at public expense.

(c) In every juvenile [*or family*] court proceeding concerning alleged child abuse or neglect in which it is a party, the local child protective service shall be represented by legal counsel [*provided by the local civil law officer of the appropriate county or comparable political subdivision or geographic area.*]

Orders Against Resuscitation: Selected Policy Statements

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Policies of Professional Societies

No Code Subcommittee, Medical-Legal Interprofessional Committee, Bar Association of San Francisco Medical Society*

The No Code Subcommittee has reviewed the policies of nine hospitals within San Francisco City and County. It is pleased to note that all general acute care institutions, with the exception of two which are parts of a larger national system (VA and US Army-Letterman), have stated a policy on this subject. However, the Committee found considerable diversity in these policies. In light of current legal opinion and ethical considerations, the Committee recommends that institutions review their policies for adequacy and accuracy. The elements of a model policy, which meets both legal and ethical requisites, are stated below with commentary. It is the opinion of the Committee that every institutional policy should reflect these elements, even though the language and emphasis might be unique to the institution. The issues of primary importance in all policies should be the patient's wishes and medical condition.

1. **A statement that Orders to Resuscitate are a standing order in the institution and that this procedure should be initiated unless there is an express order to the contrary.**

Commentary. Patients who are admitted to general acute care hospitals are to receive all procedures indicated for the treatment of their admitting diagnosis or complaint. If cardiac arrest occurs during an admission, the standard of care requires full resuscitative measures, since this event will either be unexpected or the anticipated, but undesirable, effect of their condition. Thus, each institution should have procedures for prompt response to this event and the only condition which justifies withholding this response is a written order to the contrary. In certain institutions, such as hospices, the presumption in favor of resuscitation may not be appropriate. However, all institutions providing health care should have an explicit policy.

2. **A statement regarding the patient's wishes.**

Commentary. A competent patient has the legal and moral right to refuse medical treatment, even if it is lifesaving, at any time. Thus, such a patient may exercise this right by requesting "no code" and this request should, as a general rule, be honored.

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* Final Report, the Bar Association of San Francisco Medical Society, 250 Masonic Ave., P.O. Box 18719, San Francisco, Calif. 94118 (July 20, 1982).

If the patient is competent, it is morally incumbent on the physician to inform the patient of the diagnosis of an irremediable condition and to discuss the eventuality of demise by cardiac or respiratory arrest. The patient, in such a situation, should be offered the choice to refuse resuscitation. Occasionally, the physician may judge that a discussion of this sort would so distress the patient as to render him or her incapable or a rational choice. Such judgment should be reached after thoughtful and sympathetic discussion with colleagues and with the family or friends of the patient. Even if a direct approach to the patient is judged inadvisable, a general discussion concerning the patient's preferences in advance of the critical situation is highly advisable.

The medical situation that makes a DNR order appropriate (see Section 3) will often be reached only after the patient has lost the ability to comprehend or express his or her wishes. This incapacity should be verifiable by a clinical assessment of mental and emotional status. If the patient has left advance directives, such as the directive to physicians in the California Natural Death Act, these should be honored, according to circumstances.

3. A statement of the medical conditions which should be present to justify an order not to resuscitate.

Commentary. DNR (Do Not Resuscitate) orders are appropriately recommended when the patient suffers from a known lethal disease and when further medical treatment of that disease will not, in all probability, revise the course of that disease toward the patient's death. The legal cases which have upheld no-code orders have noted that the condition of the patient should be such that death is imminent as a result of the disease. Thus, the physician makes a judgment that a point of medical futility has been reached and that any sort of intervention would, at best, only prolong the patient's dying. In a condition of such futility, an order to refrain from such stopgap measures is appropriate. Obviously, no medical judgment is absolutely certain, but the physician's experience and accumulated evidence should lend high probability to the determination that further medical treatment for the condition and resuscitation are useless in seeking the goals of medical care, such as restoration of health or satisfactory function. Thus, a policy should contain some such phrase, as, "irreversible and irremediable condition," "imminent death," etc.

4. A statement regarding the role of family or close associates.

Commentary. In many situations, patients will be incompetent to participate in a choice. The will often be surrounded by family or by friends. There are, at present, no legal grounds

to require consent for DNR orders from such persons, unless one of them has been appointed legal guardian or conservator.

However, good clinical practice requires a thoughtful and compassionate discussion with them. In addition, family and friends may be able to provide evidence of the patient's wishes, expressed to them at an earlier time. Such evidence, either verbal or written, (particularly in the form of the California Natural Death Act), while it must be carefully evaluated in the circumstances, can support the physician's recommendation not to resuscitate.

If there is disagreement among family members or between family and physician, consultation should be sought as mentioned in paragraph 7.

5. A statement regarding the entry of the DNR order in the patient's record.

Commentary. All general acute care institutions in San Francisco now require the physican to enter the DNR Order in the record. This practice, formerly avoided on the basis of fear of liability, is now universally recommended. The order and its reasons, together with comments about discussion with patients, colleagues and family, is, in fact, the best defense against liability. In addition, the order allows all who are responsible for the care of the patient to act with unanimity in this situation and avoids confusion and uncertainty. It is reasonable also to require some regular review of the order, should conditions change unexpectedly. The extent of regular review should be determined by the institution in a prudent and reasonable way.

6. A statement about the scope of the order.

Commentary. An order not to resuscitate refers strictly to the practice of cardiopulmonary resuscitation. When a patient is "full code," the entire range of procedures, as stated in Standards for Cardiopulmonary Resuscitation, (JAMA 1980; 244:453) should be followed. If the physician wishes to issue limited orders, these should be stated explicitly rather than in such cryptic and confusing terms as "partial code," "slow code," or "chemical code." Thus, if, for some reason, cardiac massage and ventilatory efforts are desirable, but intubation and pressors are not, this should be stated explicitly in the order.

Further, a DNR order does not imply a change in other clinical procedures. Thus, a patient receiving artificial ventilation or intravenous nutrition would continue to be so treated until these procedures are explicitly discontinued or a patient who is "no code" but develops an infection should be given appropriate antibiotic unless *there is a specific order not to do so.*

Finally, the modality of care subsequent to DNR order should be expressed. Namely, that all efforts to provide comfort and relief of pain will be provided. This is, of course, the highest obligation of health care professionals once their obligation to save life and restore health is extinguished by the inevitability of death.

7. **A statement regarding the obligation of various persons responsible for the care of the patient.**

Commentary. Physicians are obliged to inform others who are responsible for care of the patient about the decision not to resuscitate. The written order is only one part of the communication necessary in this case. In order to provide the best care for the patient, all who are responsible for the care of the patient should clearly understand the order and its rationale. These persons have the right to clear, definitive and written instructions. In addition, if there is a disagreement about orders, there should be an opportunity to resolve differences.

Since some cases in which the issue of nonresuscitation is raised are complex, it is advisable to institute a system to facilitate the seeking of advice and the reconciliation of differences. Some institutions have found it useful to establish a "medical ethics committee" for this purpose. Such committees can have a form and function suited to the needs and character of the individual institution.

Guidelines for Hospitals and Physicians on "Do Not Resuscitate," Medical Society of the State of New York*

The following are intended *only* to be guidelines for physicians and hospitals. Hospital medical staffs and governing bodies are encouraged to develop policies consistent with their respective by-laws and rules and regulations.

Definition

DNR (Do Not Resuscitate) means that, in the event of a cardiac or respiratory arrest, cardiopulmonary resuscitative measures will not be initiated or carried out.

Background

1. An appropriate knowledge of the serious nature of the patient's medical condition is necessary.

2. The attending physician should determine the appropriateness of a DNR order for any given patient.

* Medical Society of the State of New York, 420 Lakeville Road, Lake Success, N.Y. 11042 (Sept. 20, 1982).

3. DNR orders are compatible with maximal therapeutic care. A patient may receive vigorous support in all other therapeutic modalities and yet a DNR order may be justified.

4. When a patient is capable of making his own judgments, the DNR decision should be reached consensually by the patient and physician. When the patient is not capable of making his own decision, the decision should be reached after consultation between the appropriate family member(s) and the physician. If a patient disagrees, or, in the case of a patient incapable of making an appropriate decision, the family member(s) disagree, a DNR order should not be written.

Implementation

1. Once the DNR decision has been made, this directive shall be written as a formal order by the attending physician. A verbal or telephone order for DNR cannot be justified as a sound medical or legal practice.

2. It is the responsibility of the attending physician to insure that this order and its meaning are discussed with appropriate members of the hospital staff.

3. The facts and considerations relevant to this decision shall be recorded by the attending physician in the progress notes.

4. The DNR order shall be subject to review at any time by all concerned parties on a regular basis and may be rescinded at any time.

Do Not Resuscitate (DNR) Guidelines, Medical Association of the State of Alabama*

It is widely recognized that in some clinical situations the initiation of potentially life-prolonging treatment is inappropriate. While there may be a variety of situations in which it is justifiable to withhold or withdraw medical treatment, the guidelines presented here cover only one specific aspect of the dilemmas created by modern medical technology, issues surrounding the question of whether or not to initiate cardiopulmonary resuscitation (CPR) when the patient experiences an acute cardiac or respiratory arrest.

Definition

DNR (do not resuscitate)—In the event of an acute cardiac or respiratory arrest, no cardiopulmonary resuscitative measures will be initiated.

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* Approved by the Board of Censors, Medical Association of the State of Alabama, P.O. Box 1900-C, Montgomery, Ala. 36197 (Aug. 19, 1981).

Considerations

1. An appropriate knowledge of the patient's medical condition is necessary before consideration of a DNR order.

2. The attending physician should determine the appropriateness of the DNR order for any given medical condition.

3. DNR orders are compatible with maximal therapeutic care. The patient may be receiving vigourous support in all other therapeutic modalities and yet justifiably be considered a proper subject for the DNR order.

4. When the patient is competent, the DNR decision will be reached consensually by the patient and physician. When the patient is judged to be incompetent, this decision will be reached consensually by the appropriate family member(s) and physician. If a competent patient disagrees, or, in cases of incompetency, the family member(s) disagrees, a DNR order will not be written.

Implementation

1. Once the DNR decision has been made, this directive shall be written as a formal order by the attending physician. It is the responsibility of the attending physician to insure that this order and its meaning are discussed with appropriate members of the hospital staff.

2. The facts and considerations relevant to this decision shall be recorded by the attending physician in the progress notes.

3. The DNR order shall be subject to review on a regular basis and may be rescinded at any time.

Do Not Resuscitate (DNR) Guidelines, Minnesota Medical Association*

These guidelines have been drafted by the Ad Hoc Committee on Death of the Minnesota Medical Association. It is widely recognized that in some clinical situations the initiation of potentially life-prolonging treatment is inappropriate. While there may be a variety of situations in which it is justifiable to withhold or withdraw medical treatment, the guidelines presented here cover only one specific aspect of the dilemmas created by modern medical technology, issues surrounding the question of whether or not to initiate cardiopulmonary resuscitation (CPR) when the patient experiences an acute cardiac or respiratory arrest.

* The MMA Board of Trustees, Health Association Center, Suite 400, 2221 University Ave., S.E., Minneapolis, Minn. 55414 (Jan. 24, 1981).

Definition

DNR (do not resuscitate)—In the event of an acute cardiac or respiratory arrest, no cardiopulmonary resuscitative measures will be initiated.

Considerations

1. An appropriate knowledge of the patient's medical condition is necessary before consideration of a DNR order.

2. The attending physician should determine the appropriateness of the DNR order for any given medical condition.

3. DNR orders are compatible with maximal therapeutic care. The patient may be receiving vigorous support in all other therapeutic modalities and yet justifiably be considered a proper subject for the DNR order.

4. When the patient is competent, the DNR decision will be reached consensually by the patient and physician. When the patient is judged to be incompetent, this decision will be reached consensually by the appropriate family member(s) and physician. If a competent patient disagrees, or, in cases of incompetency, the family member(s) disagrees, a DNR order will not be written.

Implementation

1. Once the DNR decision has been made, this directive shall be written as a formal order by the attending physician. It is the responsibility of the attending physician to insure that this order and its meaning are discussed with appropriate members of the hospital staff.

2. The facts and considerations relevant to this decision shall be recorded by the attending physician in the progress notes.

3. The DNR order shall be subject to review on a regular basis and may be rescinded at any time.

Policies of Health Care Institutions

Beth Israel Hospital, Guidelines: Orders Not To Resuscitate*

I. Summary

The Medical Executive Committee has adopted guidelines for the entry of orders not to resuscitate. If questions arise which are not answered by the Guidelines, the Administrator on call should be consulted. The Committee's recommendations are described in full in the attached Guidelines.

A. Medical Record

Orders not to resuscitate (DNR) should be entered in the patient's record with full documentation by the responsible physician as to the patient's prognosis and the patient's concurrence (competent patients) or family's concurrence (incompetent patients).

B. Chief of Service

The Chief of Service (or his designee) must concur in the appropriateness of a DNR order on *incompetent* patients. This second opinion should be entered in the patient's record.

The Chief of Service (or his designee) must be notified promptly of DNR orders on *competent* patients.

C. Daily Review

All DNR orders should be reviewed daily.

D. Competent Patients

Competent Patients must give their informed consent to a DNR Order.

If, however, it is the responsible physician's opinion that a full discussion of whether CPR should be initiated would be harmful to the patient, this conclusion and its rationale should be documented. If the physician and the Chief of Service deem a DNR order appropriate, and the patient's family concurs the order may be written.

E. Incompetent Patients

The assessment of incompetence should be documented, together with the documentation of patient's medical condition and prognosis and the concurrence of the Chief of Service or his designee.

If the patient's available family agrees that a DNR order is appropriate, the order may be written.

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* Beth Israel Hospital, 330 Brookline Ave., Boston, Mass. 02215 (March 5, 1981).

If there are no available family members, the responsible physician may enter an order with the written concurrence of the Chief of Service.

Judicial Approval Required

Judicial approval should be obtained before entering a DNR order if:

1. Patient's family does not agree to a DNR order.
2. There is uncertainty or disagreement about a patient's prognosis or mental status.

The Administrator on call must be contacted on any case which warrants judicial review.

FOR FULL DETAILS SEE COMPLETE POLICY AVAILABLE AT ALL NURSING STATIONS AND DEPARTMENTAL OFFICES

II. Guidelines: Orders Not To Resuscitate

In certain circumstances it becomes appropriate to issue a "Do Not Resuscitate" (DNR) order and to enter this order in a patient's medical record. In all cases, the procedures and documentation described below should be carried out. Observe that in certain cases the Hospital Administrator on call must be contacted to assess the necessity of prior judicial approval. In all cases the Chief of Service should be kept informed as specifically listed below.

The following procedural guidelines have been adopted by the Medical Executive Committee of the Beth Israel Hospital to promote thorough decisionmaking, and to ensure accurate and adequate record keeping and the clear communication of all such decisions. When individual patient decisions present questions which are not answered by these guidelines, or when judicial approval may be required, nursing and medical staff should contact the Hospital administration through the Administrator-on-call who is available 24 hours a day.

A. The Competent Patient

A competent patient, for the purpose of these guidelines, is an adult (18 or over, or an emancipated minor) patient who is conscious, able to understand the nature and severity of his or her illness and the relative risks and alternatives, and able to make informed and deliberate choices about the treatment of the illness.

The competent patient may request the entry of a DNR order at any time without prior judicial approval. The attending physician must then consult with the patient to insure that the patient understands his or her illness and the probable consequences of refusing resuscitation treatment, that is, that the decision represents the informed choice of a competent patient. The patient's mental condition should be documented

in the medical record. If there is any question about the patient's competence, a consultation should be obtained from the psychiatry service.

The execution of a "living will," if any, should be considered by the staff, but it is neither essential nor sufficient documentation of a decision to order the entry of a DNR order.

In this circumstance, approval of the next-of-kin is not required, and their refusal of such approval is not sufficient to overrule the informed decision of a competent patient. Nevertheless, the patient's family should be informed of the patient's decision and of the Hospital's intention to abide by that decision.

In all instances where a competent patient requests entry of a DNR order, the Chief of Service or his designate must be informed promptly that such orders have been written, even though the Chief of Service cannot deny such a request from a competent patient.

If in the opinion of the attending physician the competent patient might be harmed by a full discussion of whether resuscitation would be appropriate in the event of an arrest, the competent patient should be spared the discussion; therefore if the physician and the Chief of Service deem a DNR order appropriate and the family members are in agreement that the discussion might harm the patient and that resuscitation is not appropriate, the DNR order may be entered by the physician. In such cases, the physician shall follow the procedures described below for orders on incompetent patients.

B. The Incompetent Patient

An "incompetent" patient, for the purpose of these guidelines, is a patient who is under 18 (unless an emancipated minor) or who is unable to understand the nature and consequences of his or her illness or is unable to make informed choices about the treatment of the illness.

If an incompetent patient is *irreversible and terminally ill, and death is imminent*, DNR orders may be entered without prior judicial approval, if family members concur in this decision. Before entering such an order the attending physician must consult with the patient's family including, at least, the same family members who would be sought out to consent to post-mortem examination. In addition, the attending physician should consult with, *and have the concurrence of*, the Chief of Service or his designate, before entering such orders. This second opinion as to the irreversible nature of the patient's illness and his or her moribund condition should be entered in the patient's record as well as the opinion of the first physician.

If the patient has no family who can be contacted, the DNR order may be entered by the responsible physician with the written concurrence of the Chief of Service or his designee.

C. Review

DNR orders for all patients should be reviewed at least daily to determine if they remian consonant with the patient's condition and desires. Therefore, it is most appropriate for the physician to discuss his or her opinion and decision with nursing and house staff from the outset and frequently thereafter.

D. Documentation

When a "DNR" order is decided upon, the order should be entered in the patient's chart along with the justification for the order and notes by all consultants involved. Specific reference should be made to:

1. Summary of a staff discussion regarding the patient's condition.

2. A descriptive statement of patient's competence or incompetence. For the incompetent patient, the record should include a notation of signs or conditions which indicate or constitute his or her inability to understand and make medical decisions on his or her own behalf.

3. A statement of the circumstances of the consent by the patient if the patient is competent, including staff discussions with the patient concerning the consequences of the DNR order, and any discussion with the family. For the incompetent patient, note in detail the discussions with and concurrence of all involved family.

E. Prior Judicial Approval

In any instance where judicial review is sought, the Administrator on call and the Chief of Service or his designate must be consulted in advance. The decision to seek judicial approval of an order not to resuscitate should be made jointly and hospital counsel should be consulted prior to initiating contact with the court.

Prior judicial approval should be sought if:

1. an incompetent patient is not suffering from a terminal illness or death is not imminent;

2. family members do not concur in the entry of a DNR order.

F. Support and Counseling for Patients, Families and Staff

Nothing in these procedures should indicate to the medical and nursing staff or to the patient and family an intention to diminish appropriate medical and nursing attention for the patient, whatever his or her situation.

When the incompetent patient is sufficiently alert to appreciate at least some aspects of the care he or she is receiving (the benefit of doubt must always assign to the patient the likelihood of at least partial alertness or receiptivity to verbal stimuli), every effort must be made to provide the emotional comfort and reassurance appropriate to the patient's state of consciousness and condition regardless of the designation of incompetence.

In every case in which DNR orders are issued, the Hospital shall make resources available to the greatest extent practicable to provide counseling and other emotional support as appropriate for the patient's family and for all involved Hospital staff, as well as for the patient.

City of Boston Department of Health and Hospitals, Guidelines: Do Not Resuscitate Orders*

There are circumstances in which an order not to resuscitate may properly be issued in connection with the care of a patient. In light of recent court cases, especially *In the Matter of Shirley Dinnerstein*, Department of Health and Hospitals wishes to promulgate formal guidelines with respect to Do Not Resuscitate (DNR) orders.

These guidelines apply only in the case of irreversibly, terminally ill patients. "Irreversible, terminally ill" is not further defined by law, however, the thrust of this phrase is that the law does not require a prolongation of the act of dying simply because the current state of medical technology has put measures in the physician's hands that permit the postponement of the time of death. A significant factor to be taken into account in determining whether the patient is "irreversibly terminally ill" is whether there is any treatment available that offers the patient a reasonable expectation of even a temporary return towards a normal, functioning, integrated, cognitive experience. If the physician has any questions about the meaning of the phrase "irreversibly, temrinally ill," he/she should consult with another physician.

1. In the case of a *competent*, irreversibly, terminally ill patient, a DNR order may be written upon the patient's informed consent to issue an order not to resuscitate. If the physician has any doubts whether a patient is

* Executive Committee, Medical and Dental Staff, Boston City Hospital, 818 Harrison Avenue, Boston, Mass. 02118 (Jan. 6, 1981). (signed) David L. Rosenbloom, Commissioner, Department of Health and Hospitals (Jan. 14, 1981).

competent or not, a consultation must be obtained with a psychiatrist.

2. If the patient is incompetent, or a minor and irreversibly, terminally ill, a DNR order may be written if the attending physician determines in light of the patient's history and condition and the wishes of the patient's immediate family that it would be medically inappropriate to institute efforts at resuscitation. Where possible, immediate family should be limited to spouse, children, and parents. Consent of the spouse alone should be sufficient, but if the spouse is deceased, the consent should be given by all children who have reached majority or, if there are no children, by both parents. The limitation to immediate family members is not intended to prohibit a physician from contacting other family members who the physician may feel have a close relationship with the patient and who may desire to be involved in the process.

No DNR order should be issued and an AOD [Administrative Officer of the day] should be contacted in the following circumstances:

a. no family is available,

b. only family members other than a spouse, child, or parents are available,

c. the physician wishes to issue a DNR order and faces opposition from the patient's family,

d. there is dissention among the patient's family, or

e. a competent patient has requested resuscitation and then becomes incompetent.

3. In the case where a DNR order is decided upon, the order must be recorded by the physician clearly and promptly in the patient's chart. The following must be included in the progress notes:

a. a summary of staff discussion and decision regarding the patient's condition,

b. documentation of the patient's competence or incompetence,

c. a summary of disclosures made to the patient or family,

d. a summary of the patient's or family's response,

e. *a statement of the circumstances of the consent by the patient*,

f. *signature or cosignature of Attending Staff on all DNR orders*,

g. in the case of a court order, a copy of the order should be put in the chart.

The recording requirement, whether met by "documentation," "summaries" or "statements," is fully intended to be a flexible concept requiring the establishment of a record of the events, incidents, discussions, professional decisions and their basis, which have led to the order, in a manner which is sentitive to patients and their families.

The decision not to resuscitate must be conveyed to all appropriate medical, nursing and other staff. The responsible physician should continually re-evaluate the patient's competency and consent. This must clearly be noted in the chart and, if appropriate, the DNR order revoked.

4. Any physician may contact hospital counsel directly in issues regarding DNR orders. In following these guidelines, however, all physicians are urged to contact the AOD *before* speaking with the lawyers for the Department. The role of the AOD in this process is to assist in gathering information necessary to make a full and complete presentation of the particular issue to hospital counsel, or assist in gathering information which may obviate the need to contact hospital counsel, and to provide administrative expertise which may have been gained in dealing with similar issues in the past.

Somerville Hospital, Guidelines: Orders Not to Resuscitate*

It is sometimes appropriate to issue a "Do Not Resuscitate" (DNR) order and to enter this order in a patient's medical record. In all cases, the procedures and documentation described below must be carried out. In some cases prior judicial approval is required, and in all cases the Chief of Service must be kept informed.

These guidelines have been adopted by the Medical Board and approved by the Board of Trustees to assist the medical and nursing staff in decisionmaking and in the preparation of an adequate record for the entry of a DNR order, and for the open sharing of that decision once properly made. When individual patient decisions present questions which are not answered by these guidelines, or when judicial approval may be required, nursing and medical staff should contact the hospital administration regardless of the time or day.

1. Cases Not Requiring Judicial Approval

a. The Competent Patient

* Somerville Hospital, 230 Highland Ave., Somerville, Mass. 02143 (Feb. 27, 1980).

A competent patient, for the purpose of these guidelines, is an adult (18 or over, or an emancipated minor) who is conscious, able to understand the nature and severity of the illness and the relative risks and alternatives, and able to make informed and deliberate choices about the treatment of the illness.

A competent patient may request the entry of a DNR order at any time without prior judicial approval. The attending physician must then consult with the patient to insure that the patient understands the illness and the probable consequences of refusing resuscitation treatment; that is, that the decision represents the informed choice of a competent patient. The patient's mental condition should be documented in the medical record. If there is any question about the patient's competence, a consultation should be obtained from a psychiatrist. The patient must always receive the benefit of doubt concerning competence. The irrationality from a purely medical perspective of a patient's request for a DNR order or refusal to consent to a DNR order is not sufficient in itself to deem a patient incompetent. In doubtful cases, judicial review of competence may be obtained.

The execution of a "living will" may be considered, but it is neither essential nor sufficient documentation of a decisison to order the entry of a DNR order.

In this circumstance, approval of the next-of-kin is not required, and they cannot overrule the informed decision of a competent patient. Nevertheless, the patient's family should be informed of the patient's decision and of the hospital's intention to abide by that decision.

In all instances where a competent patient requests entry of a DNR order, the Chief of Service or his designate must be informed before such orders are written, even though the Chief of Service cannot deny such a request from a competent patient.

b. The Incompetent Patient

An "incompetent" patient, for the purpose of these guidelines, is a patient who is under 18 (unless an emanicipated minor) or who is unable to understand the nature and consequences of the illness or is unable to make informed choices about treatment of the illness.

If an incompetent patient is *irreversibly and terminally ill, and death is imminent*, DNR orders may be entered without prior judicial approval. Before entering such an order the attending physician must consult with and have the consent of the patient's family including, at least, the same family members who would be sought out to consent to post-mortem examination. In addition, the attending physician should consult with, *and have the concurrence of*, the Chief of Service

or his designate, before entering such orders. This second opinion as to the irreversible nature of the patient's illness and the patient's moribund condition and imminence of death should be entered in the patient's record as well as the opinion of the first physician. If the incompetent patient has no family or the family cannot be located, hospital administration should be consulted.

c. Review

The competence of any patient previously deemed incompetent without court order should be reviewed at least daily. DNR ordrs for all patients should also be reviewed at least daily to determine if they remain appropriate to the patient's condition and desires.

The physician must discuss his/her opinion and decision concerning both competence and DNR orders with the nursing sttaff from the outset and frequently thereafter.

d. Documentation

When a "DNR" order is decided upon, the order must be entered in the patient's chart along with the justification for the order and notes by all consultants involved. Specific reference should be made to:

(l) Summary of initial staff discussion regarding the patient's condition as well as all subsequent follow-up discussions.

(2) A descriptive statement of patient's competence or incompetence. For the incompetent patient, the record should include a notation of signs or conditions which indicate the patient's inability to understand or make medical decisions.

(3) A statement of the circumstances of the consent by the patient if the patient is competent, including staff discussions with the patient cncerning the consequences of the DNR order. For the incompetent patient, note in detail the discussions with the concurrence of all involved family as well as the Chief of Service or his designate.

2. Illustrative Cases of the Incompetent Patient Requiring Prior Judicial Approval

a. When a patient is terminally ill but there is a chance of remission if treatment is adminsitered, a decision to withhold resuscitation requires prior judicial approval. Even if the patient's next-of-kin assents, the physician may not withhold resuscitation without a court order.

b. When a patient is acutely but not terminally ill (in need of medical intervention or death will soon occur), and the quality of the life saved would be marginal, the decision to withhold resuscitation must have prior judicial approval.

c. When family members persist in demanding, for a terminally ill, dying patient, resuscitative efforts or DNR orders which are clinically inappropriate or not in the patient's interest, staff should consult hospital administration concerning judicial review of the patient's condition.

d. In any instance where judicial review is sought, the Chief of Service or his designate must be consulted in advance.

e. These guidelines may not be used to discontinue life supporting therapies or equipment. Should such questions arise, hospital administration should be consulted.

3. Other Important Considerations

Nothing in these procedures should indicate to the medical and nursing staff or to the patient and family an intention to disminish appropriate medical and nursing attention for the patient, whatever the situation.

When the incompetent patient is sufficiently alert to appreciate at least some aspects of the care being received, every effort must be made to provide emotional comfort and reassurance appropriate to the patient's state of consciousness and condition. Unless it is clear to the contrary, the patient should always be presumed to be at least partially alert and receptive to verbal stimuli.

In every case in which DNR orders are issued, the hospital shall make available, to the greatest extent practicable, resources to provide counseling and other emotional support as appropraite for the patient's family and for all involved hospital staff, as well as for the patient.

(Signed)
Norman E. Girard
President

Guidelines for "No-Code" Orders in Los Angeles County Department of Health Services' Hospitals*

Cardio-Pulmonary Resuscitation (CPR) is unique among therapeutic modalities in that it is initiated without a physician's order when cardiac or respiratory arrest is recognized. A specific instruction is necessary if CPR is not to be initiated.

The term, "No-Code Order," refers to the suspension of the otherwise automatic initiation of CPR.

* Los Angeles, Calif. (July 5, 1979).

"No-Code" Order will be considered only when there is an underlying incurable medical condition and when death is expected, imminent and inevitable.[1]

A "No-Code" Order may be considered when a patient's physician feels that CPR is not indicated should the natural course of a patient's medical condition cause vital functions to fail. Before the order is written, the patient, if competent, will be consulted. If the patient is a minor or has been adjudicated incompetent, or adjudicated to lack the capacity to make medical decisions, the patient's guardian or conservator will be consulted. If a competent patient or a legal guardian or conservator disagrees, the order will not be written. In all cases, the wishes of the immediate family should be given very great weight in arriving at the decision.

The physician will write and sign the order on the Physician Order Sheet. Physicians in training (interns and residents) must obtain concurrence from a member of the attending staff before the order is written. The circumstances surrounding the "No-Code" order will be documented in the progress notes. Documentation must include but not be limited to:

a. A summary of the medical situation.

b. The outcome of consultation with other physicians.

c. A statement summarizing outcome of consultations with patient, guardian, conservator or family.

The order must be reviewed periodically as medically indicated.

Every necessary measure will be taken to relieve the patient's suffering and to maintain the patient's comfort.

CPR will be initiated automatically if there is no written and signed "No-Code" Order on the order sheet.

Northwestern Memorial Hospital, Do Not Resuscitate Orders*

I. Purpose

It is the purpose of this policy to enunciate clearly the practice which should be followed when a member of the

[1] An exception may be made when a competent, knowledgeable patient has clearly expressed the desire that no CPR procedures be instituted in specified circumstances. Consultation with hospital counsel is suggested to insure appropriately documented informed consent.

* Northwestern Memorial Hospital, 303 East Superior St., Chicago, Ill. 60611 (March 15, 1978).

Medical Staff issues an order that "heroic" or extraordinary means should not be employed on behalf of his patient. Such orders are often colloquially referred to as "Do Not Resuscitate" orders, but it should be understood that the use of the words "Do Not Resuscitate" is not determinative of the policy or the issues involved. The writing of any order, irrespective of the language used, which has the effect of precluding the use of extraordinary or "heroic" measures to maintain life is covered by this policy.

II. Definition

For purposes of this policy, "resuscitation" will be defined as any extraordinary or "heroic" means employed to maintain the life of a patient including any *one* of the following: intubation/ventillation, closed chest cardiac massage, and defibrillation. Resuscitation does *not* mean or refer to ordinary or reasonable methods used to maintain life or health.

III. Written Order

All orders not to resuscitate a patient *must* be written or signed by the member of the Medical Staff attending the patient on the Physician's Order Sheet in the patient's medical record. The writing of the order in any other document (e.g. Kardex) will be violative of this policy. *Failure to write such an order in the chart will result in the initiation of resuscitative measures.* In addition to the order itself, physicians may wish to write an entry attendant to the order in the progress notes which includes the following information:

1. A short description of the patient's physical condition corroborating the terminal prognosis.
2. Reference to any consultations which corrborate a DNR order.
3. Reference to any discussions concerning the prognosis or the DNR order with the patient, his family, conservator or guardian.

Such an entry is *not* legally required, for it should only constitute a distillation and/or restatement of information found elsewhere in the patient's record, but it may be made if the member of the Medical Staff desires.

IV. Communication With Patient and Family

Physicians should realize that members of the patient's family either individually or collectively do not necessarily have a legal right to impose their wishes or decisions either on a physician or his patient as to the care to be rendered to that patient. If the patient is an adult, the decision not to resuscitate need only be discussed with him, or, in the event that the patient has been adjudged to be mentally incompetent by a court of competent jurisdiction, with the patient's guardian or conservator. In the event that the patient is a minor (under the age of 18), the decision need only be discussed with the minor's

parent or legally appointed guardian. (In the event the minor's parents are divorced, the physician should discuss the decision with the parent who has been awarded custody of the minor.) Conversations and discussions with family members who do not have the legal authority to act for the patient may be advisable for a variety of reasons, but are not necessarily legally binding upon the physician.

V. Verbal Orders

Verbal DNR orders can be received only by a licensed physician and must be witnessed by *two* other individuals. These individuals must each individually hear the order and document it with the physician's order in the chart. Verbal or telephone orders must be authenticated and countersigned by the member of the Medical Staff attending the patient within twelve hours.

DO NOT RESUSCITATE ORDERS (Supplement #1 to policy of same title and number dated March 15, 1978)
July 1, 1978

The following is an addendum to policy 5.53.

1. The DNR order must be written and signed by an attending physician in the physician's order sheet. The order is invalid if written anywhere else.

2. Verbal order must be written only by a licensed physician and must be witnessed by two other individuals who personally hear and document the order. Verbal order must be countersigned by an attending physician within twelve hours of its being given. If it is not countersigned within that time period, it is invalid.

3. Failure to comply with paragraphs one and/or two result in the patient being resuscitated.

4. Explanatory notes may be written in the progress notes by the attending physician.

5. As used in this policy, the term "Medical Staff" means attending physicians *only*. It does not include resident physicians.

(signed)
David L. Everhart

University of Wisconsin Hospital and Clinics, Guidelines Regarding Decisions to Give, Withhold or Terminate Care*

I. Purpose

A. To establish guidelines for making decisions to give,

withhold or terminate care to a specific patient.

B. To determine if care is to be given, withheld or terminated depending first on the *competence* of the patient.

1) Competence is defined as the mental ability to know reality so that the nature and effect of illness and treatment can be understood and decisions made which are a product of a reasoning thought process.

2) Competence to make medical decisions may be an inherent quality of mature minors and persons legally incompetent, *e.g.*, children, prisoners and those under guardianship, or persons legally incompetent during some periods of time and not others; however, these cases must be handled carefully and on an individual basis.

II. Policy

A. Generally, decisions are made as follows for *competent patients:*

l) If a patient is fully informed and *competent*, his/her wishes, however unconventional, must be obeyed except where danger of suicide exists. (See A 3 below) Competence to make decisions about medical care is a factual/medical question in each case; where competence is unclear, emergency medical treatment should be given even against the patient's apparent will. A consultation is recommended.

2) Whether the patient is competent or incompetent, violent behavior may always be controlled with medication, if necessary. Protection and Security should be called for help when needed.

3) Where danger of suicide exists, steps to prevent it should be taken, pending a decision regarding presence of mental illness (not competence) and of immediate risk to the patient.

B. If a patient is *incompetent*, terminating or withholding care is reasonable where the following conditions are true: (below)

1) Patient is terminally ill and irreversibly incompetent; patient is expected to die within two weeks despite maximum medical care. It is recommended that consultation be obtained regarding determination of irreversible incompetence and terminal illness.

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* Center for Health Sciences, University of Wisconsin-Madison, 600 Highland Ave., Madison, Wisc. 53792 (effective Dec. 1980; as of March 10, 1983, this policy was undergoing revision; the proposed changes involve procedural steps, however, that do not affect the substance of the policy.)

2) Patient is irreversibly comatose even though death is not foreseeable in the near future.

3) Care will prolong a painful dying process with little possibility of benefit. Whether or not a patient may benefit from medical care is a value judgment and not simply a question of whether life can be prolonged.

and if 4) or 5) is also true:

4) Patient has previously indicated orally or in writing that s/he would wish to have care terminated in his/her present circumstances.

5) In the absence of such a previous statement by the patient, his/her family or other appropriate person (see below) desire that care be terminated or withheld.

6) In case of death, including brain death, no consent is necessary to discontinue care.

C. If a patient is incompetent, terminating or withholding care is *clearly unreasonable* (regardless of family wishes) if any one of the following is true:

1) patient appears terminally ill but a reasonable hope of temporary remission exists, or there is some possibility of cure; many patients elect to undertake treatment in this situation.

2) The incompetence is temporary and the decision can wait.

3) The patient has previously requested full treatment under the circumstances at hand, and the patient's physician did not clearly decline to be bound by such wishes.

4) The proposed care is accepted medical practice (benefits outweigh risks). Objections to such care, even if based on religious grounds, prevail only when made by the fully competent patient.

D. Giving care against an incompetent patient's apparent will is reasonable if:

1) There is sound reason to believe that care will benefit the patient, outweighing risks, and is generally accepted medical practice in such cases.

2) It is especially permissible in situations where the patient has previously, while competent, asked that care be given in the now present circumstances, or

3) Appropriate spokespersons (see below) agree that care should be given.

E. Decisions about care of an incompetent patient should be made by other persons in the following priority order:

1) Guardian, if appointed

2) Spouse

3) Adult son or daughter

4) Parent

5) Adult brother or sister

6) Other close relative or close friend

When caring for incompetent patients, it is always appropriate to obtain the consent of such a spokesperson. Where none are available, or when a natural representative of the patient is acting unreasonably, the physician may be required to seek the court appointment of a guardian, especially in cases of long-term care.

F. Addendum

1) Where nontreatment is reasonable, *i.e.*, the patient would probably elect nontreatment if competent, others may act for the patient without court action. If the patient by previous expression, physician and family agree that withholding treatment is the proper choice, little likelihood exists that such a decision will be challenged. The physician's decision, however, must be based on a determination that it is generally accepted medical practice to elect nontreatment in this situation.

2) If it is unclear whether nontreatment criteria are satisfied, continue care for the time being. If prognosis or accepted therapy is in doubt, consult with other physicians either informally or by committee. If prognosis is certain but family consent to termination or withholding of care is absent or doubtful, or if intra-family conflicts exist, attempt to obtain the family's consent; failing that, after adequate efforts, petition Probate Court for appointment of guardianship; the guardian will make decisions for the patient.

3) Those persons who have a court-appointed guardian (most prisoners referred for medical care) should not suffer medical disadvantage because of their legal (or prisoner) status. Where care is medically necessary, consent of the patient in such cases will be sufficient if they possess actual (as opposed to legal) competence.

4) Next of kin may insist on their legal right to speak for the patient; however, only court-appointed guardians may speak for adults with full legal authority. Parent's authority is conditioned on their legal duty to provide necessary medical care for their children, even if defective or potentially retarded. Physicians have direct obligations to their patients and should not permit unreasonable family pressure or threat of legal action to delay or deter action in the best interests of the patient. In general persons who act for incompetent patients must do so reasonably to retain their status as the patient's representative.

5) The advice and counsel of colleagues should normally be sought in difficult cases and legal advice obtained as indicated.

IV. To terminate or withhold care:

A. Document patient's condition, prognosis, mental status, consultations and treatment options in the clinical record.

B. Include patient's prior instructions (document patient's competency when making them) or consent of family, guardian (or court) in patient's clinical record.

C. Enter orders such as "No Bluecart" on Kardex or patient's refusal of care on consent form, and verbally inform health care team that this has been done.

D. Discontinue treatment, if appropriate.

V. Approved by UWHC Medical Board (August 1980).

(signed)
Gordon M. Derzon,
Superintendent

Statements Concerning Federal Agencies

Veterans Administration, Chief Medical Director's Letter on "No Code" and other Similar Orders*

1. Technological advances in medicine are usually hailed as providing great new benefits for patients. Often the social, moral, ethical and financial impact of these same advances are not perceived until years later. Perhaps some of the most perplexing issues before us today have followed in the wake of our ability to delay the moment of death by the application of a variety of technological devices. Professional publications, the news media and the law have wrestled with, and given visibility to, many of these issues. The heightened awareness of these issues has raised questions from many anxious health care professionals: *viz.*; when should support for a terminally illpatient be discontinued, who is responsible for such a decision, what are the legal liabilities of various persons under such circumstances and can a doctor order other providers (doctors or nurses) to refrain from doing something they (the providers) feel conscience bound to do? We recognize these genuine expressions of concern on the part of every health care professional but are unable to resolve most of these controversies.

2. It is worthwhile, however, to simply state that the policy of the Veterans Administration's Department of Medicine and Surgery should continue to be consistent with those ethical principles adhered to by the medical and allied professions. We should also make accommodations for those state laws which provide for certain defined rights of patients but we must also give recognition to the rights of others, including family members and health care providers, in the exercise of their religious and moral beliefs.

3. In a few states, the legislatures have enacted "Natural Death" or "Death with Dignity" statutes. Our VA medical centers located in such states are already under the direction of DM&S Circular 10-79-160, dated July 25, 1979, Subj.: "State laws regarding the withholding or withdrawal of life-sustaining procedures." Although the majority of our medical centers are not affected by such legislation, they may be affected by a variety of other local laws (*e.g.*, "Brain Death"). Nevertheless, it must be remembered that every competent adult patient usually has the right to refuse any medical treatment offered, even if that refusal might result in death.

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* James C. Crutcher, M.D., Chief Medical Director, Department of Medicine and Surgery, Veterans Administration (Washington, D.C. 20420) Doc. No. IL 10-79-66 (Nov. 20, 1979).

4. In some of our medical centers a few physicians have felt compelled, under certain circumstances, to write "no code" orders. Such orders may direct someone (usually a member of a nursing staff) to refrain from performing an act which their conscience dictates be done or may intimidate someone who, in the absnce of such an order, would normally have performed the act. We believe such orders are inappropriate and do not contribute to high quality patient care. The preferable alterantive is to permit health care professionals in such situations to be free to exercise their judgment guided by their education, experience and ethical and moral persuasion.

5. On the other hand, it is essential that the progress notes entered in the record for a terminally ill patient be fully informative of the diagnosis, the prognosis, the patient's wishes (when known), the wishes of the family members and the recommendations of the attending staff (not resident) physician. With a well documented record, the choice to "code" or "no code" will remain one of professional judgment on the part of the appropriate health care provider caring for the patient at the time of cardiopulmonary arrest.

6. Compassionate care of the sick guided by the high ethical standards demanded of doctors and nurses for centuries will continue to be the best policy. With the same dedication with which we provide high quality care to patients who survive their illness, we will find satisfaction in the knowledge we have done the best possible to provide comfort, compassion and dignity for those who do not survive.

National Institutes of Health, The Clinical Center*

PURPOSE

The purpose of this communication is to institute a mechanism whereby requests not to administer cardiac resuscitation can be brought to the attention of all those who might be required to respond.

DELEGATION OF AUTHORITY

Pursuant to its responsibilities for developing policies concerning medical practice, the ultimate responsibility for making policy decisions concerning orders not to attempt cardiac resuscitation shall belong to the Medical Board. The Board delegates operating responsibility for the conduct of this policy to Clinical Directors, and through them to attending

* Medical Administrative Policy No. 82-4, Subject: Orders Not to Attempt Cardiac Resuscitation Policy and Communications Bulletin, Medical Administrative Series (July 12, 1982).

physicians. In the case of dispute or doubt, an *ad hoc* advisory committee of physicians, nurses, social workers and others may be formed at the request of the family, medical or hospital staff, or members of the Board.

POLICY STATEMENT

A note indicating that the physician had approached the patient on this subject shall precede the order in the chart. If the patient is an unemancipated minor or is unable to understand the nature and consequences of his or her illness, or is unable to make informed choices about the treatment of the illness, the patient's next of kin or legal guardian shall be approached. If the patient has no next of kin or legal guardian who can be contacted, the Do Not Resuscitate (DNR) order may be entered by the responsible physician with the written concurrence of another member of the senior staff and the Clinical Director.

If in a physician's judgment a patient should not receive cardiac resuscitation, a progress note written by the attending and senior physician, and an order to that effect, should be written in the patient's chart. All such orders shall be signed by the attending physician and another member of the senior staff familiar with the particular circumstances. The order not to resuscitate would then be entered into MIS [Medical Information Systems Service].

Absence of an order not to attempt cardiac resuscitation shall be interpreted by the nursing staff as requiring such efforts should the patient have a cardiac arrest.

Department of the Army, Surgeon General's Letter on the Texas Natural Death Act*

1. Neither the "Directive to Physicians" (State of Texas Natural Death Act) nor any similiar directives regarding the withholding or withdrawal of life-sustaining procedures will be accepted or honored by Army Medical Treatment Facility [MTF] personnel.

2. The Texas Natural Death Act (TNDA) has been thoroughly evaluated by the Office of the Judge Advocate General. It appears that a "Directive to Physicians" executed in accordance with the TNDA would be legally effective only in the case of a physician licensed in the State of Texas, who is not a member of the Armed Forces, and who is practicing in an area over which the United States holds only a proprietary interest.

* DASG-PSA (13 Dec 77) 1st Ind; DA, OTSG, Washington, D.C. 20310, To: Commander, US Army Health Services Command, ATTN: HSJA Fort Sam Houston, TX 78234 (May 23, 1978).

3. MTF's may be located on land under various kinds of Federal legislative jurisdiction: exclusive jurisdiction, concurrent jurisdiction, partial jurisdiction, and prioprietary interest only. "Exclusive Federal jurisdiction" means that *only* the Federal Government may legislate as to the area in question. "Concurrent jurisdiction" means that both the Federal Government and a state government may legislate as to all matters within the area. "Partial jurisdiction" means that at least one of the two governments may legislate as to some, but not all, questions with regard to the area. "Proprietary interest only" means that the Federal Government owns or has an interest in the land in question but has acquired none of the state's power to legislate with respect to it. It is likely, but not certain, that in at least some cases, in the absence of the TNDA, the deliberate withholding or withdrawal of medical attention resulting in the death of a patient would be a criminal homicide under both State and Federal law. Section 6 of the TNDA immunizes certain "physicians" and "health professionals" from criminal liability for the non-negligent compliance with a properly executed Directive. But, there are specific Federal statutes against homicide in areas of exclusive Federal or concurrent (and, perhaps, partial) jurisdiction (18 U.S.C. 1111-1113). The TNDA cannot affect these Federal statutes because the State of Texas cannot change Federal laws. Accordingly, whether compliance with a directive resulting in a patient's death is a crime may depend on the type of jurisdiction on which the MTF is located. Furthermore, portions of many military installations were acquired at different times and are subject to different forms of jurisdiction. Thus, it is possible for one part of a single MTF to be under exclusive Federal jurisdiction and another part to be subject to only a Federal proprietary interest.

4. To complicate the situation further, the effect of a TNDA directive may depend on the status of the physician in question.

a. Military physicians. While applicability of 18 U.S.C. 1111-1113 depends on the nature of Federal jurisdiction over the place, the Uniform Code of Military Justice (UCMJ) is applicable to active duty members of the Armed Forces acting in their official capacities regardless of their location. It has not been authoritatively decided that allowing a patient to die in compliance with a TNDA Directive would be a crime under the UCMJ, but that is a possibility. That the same act would not be a crime under a law of the state where it occurred is immaterial. Thus, a military physician could be subject to prosecution for homicide regardless of whether he was licensed in Texas and regardless of the nature of jurisdiction over the MTF where the act occurred.

b. Civilian physicians. The applicability of the TNDA to civilian physicians would depend on the nature of jurisdiction

over the place and whether the physician is licensed in Texas or in another state. As Section 2(4) of the TNDA defines "physician" as a physician or surgeon licensed by the Texas State Board of Medical Examiners, a civilian physician licensed by another state working in a MTF in Texas would not be considered a physician for purposes of the TNDA. The Act provides immunity only for "physicians" and "health professionals acting under the direction of a physician." The term "health professional" is not defined in the TNDA, and it is uncertain whether it would include non-Texas civilian physicians. If it did not, a non-Texas civilian physician complying with a TNDA Directive in an area under the criminal jurisdiction of Texas could be subject to prosecution by Texas for homicide.

5. Based on the discussion above, it is clear that the only possible uniform rule for dealing with TNDA Directives, and similar state directives, is to prohibit their use in Army MTF's. Any other approach would create an impossible situation from the standpoints of both medical and legal administration of MTF's.

6. Request this policy be given appropriate dissemination.

(signed)
ENRIQUE MENDEZ, JR., M.D.
Major General, MC
Acting The Surgeon General

Letter from James G. Zimmerly, M.D., J.D. to the Surgeon General, Department of the Army*

SUBJECT: Termination of Life Support and Entering of No-Code Orders

LTC Bernhard T. Mittemeyer, MC, USA
The Surgeon General
Department of the Army
Room 3-E-469
Washington, D.C. 20310

1. We are writing to express our concern regarding policy DAGS-PSA (13 Dec 77) lst Indorsement (Inclosure #1) regarding application of the Texas Natural Death Act and similar directives in Army Medical Treatment Facilities. In particular our concerns are as follows: 1) the policy has caused great confusion in military treatment facilities and is being given

* (April 1, 1982).

different applications; 2) the policy is contrary to both established legal principles and a developing body of case law on point; 3) continuation of the policy is exposing the United States of America and its agents to civil liability; 4) fears of criminal prosecution are unjustified. Each of these concerns will be addressed more fully as follows:

A. The policy has caused confusion in military treatment facilities (MTFs)

Some MTFs have interpreted the policy to mean that their medical personnel cannot enter "no-code" orders on any patient or either withhold or withdraw extraordinary life-support measures from any patient under any circumstances. At least one MTF that has come to our attention is completely ignoring the policy. What has become clear is that most MTF medical personnel and JAG officers are quite confused as to how strictly the policy is to be interpreted. Particularly confusing is the language "similar directives." Does this mean directives exactly like that encompassed in the Texas Natural Death Act or *any* type of request from a terminally ill patient to cease or not begin treatment? At the very least this policy must be clarified.

B. The policy is contrary to established principles of medical law

A basic tenet of medical law is that any adult of sound mind may refuse medical treatment, even if such refusal would result in the person's death. One recent case illustrating this principle is "In the Matter of Robert Quackenbush, an alleged incompetent," 383 A.2d 785 (1978). In *Quackenbush* a 72-year old patient refused to consent to the amputation of his gangrenous legs. The hospital sought a court order to do so alleging that the patient was incompetent and that failure to have the operation would result in the patient's death. The court ruled that the patient was, in fact, competent and that as a competent adult he had the right to make an informed choice about treatment even though the choice would lead to his death.

In federal law, the United States Supreme Court has stated in two landmark cases that there is a right to privacy under the United States Constitution. Therefore, governmental interference with medical treatment arranged between a physician and his or her patients would be a violation of the patient's constitutional right to privacy absent a compelling state interest. *Griswold v. Connecticut*, 381 U.S 479, 85 S. Ct. 1678, 14 L.Ed.2d 510 (1965) and *Roe v. Wade*, 410 U.S. 113, 93 S. Ct. 705, 35 L.Ed.2d 147 (1973). Other federal cases have held that patients have the right to refuse medical treatment. *Winters v. Miller*, 446 F2d 65, cert. denied, 404 U.S. 985, 92 S.Ct. 450, 30 L.Ed.2d 369 (1971) and *Rogers v. Okin*, 634 F.2d 650 (1980).

Of the few cases that take a contrary position most have involved either a pregnant woman or a parent with minor children. In those cases, the courts found that the state had a compelling interest in seeing that the parent stayed alive to give birth to or take care of the child involved. *Raleigh Fitkin-Paul Morgan Memorial Hospital v. Anderson*, 42 N.J. 421, 201 A.2d 537, cert. den. 377 U.S. 985 (1964).

Finally, AR 600-20, paragraph 5-29 states that "An Army member on active duty or active duty for training will *usually* be required to submit to medical care considered necessary to preserve his life, *alleviate undue suffering*, or protect or maintain the health of others." (Emphasis added.) The word "usually" leaves the door open for exceptions to the rule that life-preserving treatment can be rendered without consent. Surely either a terminally ill patient or a patient in an irreversible comatose state would fall into the exception. The rule also states that medical care can be given without consent in order to "alleviate undue suffering." It would make sense that the converse would also be true. That is, that further medical care would not be given to a patient dying of a painful disease in order to "alleviate undue suffering," Further, paragraph 5-29 defines medical care as "...preventive, diagnostic, therapeutic, and rehabilitative medical, surgical and psychiatric and dental treatment." It can certainly be argued that extraordinary life support measures do not fall within this definition. Finally, in discussing referral of a serviceman to a medical board for refusal to submit to medical treatment, paragraph 5-31 states that the medical board must answer the following question: "(1) is the proposed treatment required to relieve the incapacity and aid the soldier's return to a duty status, and may it be expected to do so?" Obviously, if the patient was terminally ill or in a permanent comatose state, the answer would be "No." As such a solider would never be able to return to a duty status, the United States Army would not have a compelling government interest in forcing such a patient to submit to medical care against his or her wishes.

C. The policy is contrary to a growing body of case law dealing directly with no-code orders and the right of a terminally ill or comatose patient to refuse life-sustaining treatment

1. Eight major state court decisions have been rendered which are applicable. They have predominately upheld the right of a competent adult or person acting on behalf of an incompetent adult, to refuse further treatment. The cases are as follows:

a) *In the Matter of Karen Quinlan, An Alleged Incompetent*, 70 NJ 10, 355 A.2d 647, 79 ALR3d 205 (1976)—the Supreme Court of New Jersey held that a 22-year old patient in a comatose state had a constitutional right to privacy and,

therefore, could have life-sustaining apparatus discontinued, through her guardian, if hospital ethics committee and attending physicians agreed that there was no reasonable possibility of her ever emerging from her comatose state. The court made clear that this was a decision to be made between physicians and patients, and that no court order was necessary.

b) *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977)—the court gave permission to the guardian of a 67-year old mentally retarded patient dying of acute myeloblastic monocytic leukemia to refuse painful chemotherapy treatment on behalf of the patient. The court applied the "substituted judgment doctrine," that is, what the patient would have wanted if competent. The court also based its decision on the constitutional right to privacy.

c) *In re Shirley Dinnerstein*, 380 N.E. 134 (1978)—the court held that a physician attending an incompetent, terminally ill patient may lawfully direct that resuscitation measures be withheld in the event of cardiac or respiratory arrest *without prior court approval.*

d) *Satz v. Perlmutter*, 362 So.2d 160 (1978), aff'd Fla. Supreme Ct. 379 So.2d 359 (1980)—held that a competent 73-year old patient suffering from Lou Gehrig's disease could have respirator removed from his trachea even though such removal would result in life expectancy of less than one hour. The court based its decision largely on the constitutional right to privacy.

e) *Severns v. Wilmington Medical Center*, 421 A.2d 1334 (1980); 425 A.2d 156 (1980)—husband was allowed to assert constitutional right to privacy of comatose wife and, therefore, could instruct medical authorities not to place her on a respirator, not to surgically replace a feeding tube, not to administer any drugs or medicine other than those normally used for bodily hygiene, and finally that a so-called no-code blue order be entered on her medical chart.

f) *In re Spring*, 399 N.E.2d 493 (1979), 405 N.E.2d 115 (1980)—guardian allowed to end dialysis treatment of a 77-year old man suffering from end stage renal disease and organic brain syndrome. Decision based in part upon federal constitutional right to privacy.

g) *Matter of Storar; Eichner v. Dillon*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, (1981); see also Appellate Division opinion *In re Eichner "Brother Fox,"* 73 A.D.2d 431, 426 N.Y.S. 2d 517 (1980)—83-year old patient, prior to becoming incompetent due to illness, had consistently expressed his views that his life not be prolonged by medical means if there was no hope of recovery. Therefore, guardian was allowed to obtain discontinuance of patient's respirator on which patient was being maintained in a permanent vegetative state.

h) *Leach v. Akron General Medical Center*, 426 N.E.2d 809, 68 Ohio Misc. 1 (1980)—guardian of patient who was

terminally ill and in a permanent vegetative state was granted order to have the patient removed from a respirator when it was shown that the patient, if competent, would have elected not to be placed on life supports.

2. Although there is no federal case law directly on point, six of the eight state cases cited above based their decisions at least in part on the federal constitutional right to privacy enunciated in the two U.S. Supreme Court cases, *Griswold v. Connecticut* and *Roe v. Wade*, supra. Therefore, it is inconceivable that a federal court would not uphold the right of a competent, terminally ill patient (through his or her guardian if incompetent) to refuse further medical treatment.

D. The policy exposes the United States of America and its agents to civil liability

1. Several federal courts have held that providing medical care that has not been consented to constitutes an assault and battery. In *Mink v. University of Chicago*, 460 F.Supp. 713, (1980) the plaintiffs brought a class action suit on behalf of themselves and approximately 1,000 other women who had been given DES without their consent as part of a double blind study. The federal court ruled that the plaintiffs had a cause of action for battery. In *Hernandez v. United States America*, 465 F.Supp. 1071 (1979) a federal court ruled that an unconsented to operation performed in a Veterans Administration Hospital constituted an assault and battery. The court further ruled that a claim for assault and battery was not cognizable under the Federal Tort Claims Act due to the exception to such an action found in 28 U.S.C. § 2680(h). However, the court noted a few cases wherein the plaintiffs managed to get around this section in medical cases based upon negligence theory. *Lane v. United States*, 225 F.Supp. 850 (1964); *Fontenelle v. United States*, 327 F.Supp. 80 (1971).

There is also a distinct possibility that military medical personnel involved in rendering unconsented to treatment to a terminally ill or comatose patient could be held individually liable since an intentional assault and battery is generally considered to be outside the scope of a federal employee's practice and therefore coverage would not be available under the *Gonzales Act*, 10 USC § 1089.

2. It has come to our attention that at one particular MTF several families have threatened to bring suit against the U.S. Government because the MTF will not honor any directives to terminate life-support, executed in accordance with that state's natural death legislation. It has also come to our attention that, in fact, the Veterans Administration has recently been sued successfully based upon somewhat similar circumstances. The case, *Foster v. Tourtellotte, et al.*, (1981-82) U.S. District Court, Los Angeles, Hon. Robert Takasugi, Judge, was filed in October of 1981 when VA medical personnel refused to remove a

patient dying from Lou Gehrig's disease from a ventilator at his request. The plaintiff filed a complaint alleging battery, breach of fiduciary duty, violation of constitutional right of privacy, and for injunctive and declaratory relief. In support of his request to be removed from the ventilator, the plaintiff asserted his constitutional right to privacy and his common law right to refuse medical treatment.*

In granting an injunction and ordering the defendants to disengage the plaintiff from the ventilator, the court held "...as we balance the contentions of plaintiff with the concern of society for the life prolongation, this Court cannot conceive a real, substantive collision of philosophies because a reasonable society could not mandate Mr. Foster to bear the unbearable or tolerate the intolerable... Whether Mr. Foster experiences subjective pain at this time, I don't think is truly the issue. He has asserted his constitutional rights of self-dignity to demand that future medical care be terminated." *Foster*, at 22-23. Although the plaintiff's stated causes of action were not cognizable under the Federal Tort Claims Act, and he was therefore not entitled to monetary damages, the plaintiff's attorney is appealing the decision not to grant him attorney's fees which he may be entitled to. More importantly, the suit brought extremely adverse publicity to the Veterans Administration.

In conclusion, it is conceivable that military medical personnel could be sued successfully on an individual basis, and be held personally liable, on the theory of an intentional assault and battery. There is a further possibility that the United States could be sued successfully. Even if monetary damages were not awarded, patients could seek injunctive relief which would engage the United States in costly litigation and further result in adverse publicity.

E. Fears of criminal prosecution are unwarranted

The JAG [Judge Advocate General] opinions upon which the policy in question is based are primarily concerned with criminal prosecution under state laws, federal laws, and the Uniform Code of Military Justice (UCMJ). The theories of criminal liability would be assisting a suicide and homicide.

1. *State Law* —Twenty-three states currently have statutes against assisting suicide. An extensive search of cases over the past fifteen years revealed only a few reported cases that have ever been prosecuted under these statutes, none of which dealt in any way with a terminally ill patient or a physician. The only reported case having even a remote

* A number of the arguments that the plaintiff successfully used in *Foster* have subsequently been used herein. Copies of all of the briefs filed in and on behalf of *Foster* are available for inspection at the Armed Forces Institute of Pathology.

connection took place in 1920 in the case of *People v. Roberts*, 211 Mich. 187, 178 N.W. 690. *Roberts*, a husband, was prosecuted for administering poison to his dying wife at her request. The case did not involve physicians or extraordinary life support.

Under the case law reported in section C. above, a physician would not be guilty of homicide if he were operating under guidelines established in accordance with the said law. (To be discussed, *Infra.*)

2. *Federal Law* —Assisting a suicide is not a crime under the federal code. An extensive search of reported cases revealed no federal cases wherein a federally employed physician was ever prosecuted for homicide for either terminating or withholding life support of a terminally ill patient, or for entering a "do not resuscitate" order in a patient's chart. Further, such a prosecution would be inconceivable if the physician were following guidelines established in accordance with reported cases on the subject.

3. *UCMJ* —Assisting a suicide is not listed as an offense under the UCMJ. Extensive research did not reveal any cases wherein a physician was prosecuted under the UCMJ for homicide for either terminating or withholding life support of a terminally ill patient, or for entering a do not resuscitate order in a patient's chart. Clearly, if the Surgeon General issued a policy setting forth appropriate guidelines for dealing with terminally ill patients, any physician following the guidelines would not be subject to prosecution under the UCMJ.

Conclusions

1. The Department of the Army must develop guidelines for handling terminally ill patients in MTFs that are in accordance with applicable state and federal case law

The eight cases mentioned in section C. above set forth certain methods of handling terminally ill patients consistent with the right of such patients to refuse treatment. In addition, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research has formulated a draft paper, dated January 8, 1982, entitled "Resuscitation and the Decision Against." This paper is an example of the type of guidelines that the Department of the Army should formulate. Numerous other writings and research exist which can give the Department of the Army guidance on formulating appropriate guidelines that would be consistent with the current state of the law on this subject.

2. State directives should be honored in MTFs

Natural Death Legislation has been enacted in eleven states and is being considered in others. The scope of most of these acts is quite limited. If the Department of the Army had its own broad guidelines, execution of a state directive with its

limited scope of application would be covered under the guidelines. Even in the absence of appropriate Army guidelines, criminal prosecution for following such directives is unlikely for the reasons stated above.

2. The Department of Legal Medicine stands ready to discuss this matter further, to assist in the development of appropriate guidelines, and to provide any other necessary expertise.

(signed)
James G. Zimmerly,
M.D., J.D.,
MPH, Col, MC, USA
Chairman, Dept. of Legal Medicine

Prepared by:

(signed)

Jane G. Norman, J.D.
Department of Legal Medicine

Department of the Navy, National Naval Medical Center*

1. Purpose. To establish guidelines for writing orders not to resuscitate ("no code" orders).

2. Background. The routine applicaton of cardiopulmonary resuscitation and Advanced Cardiac Life Support has given rise to serious questions regarding the appropriateness of resuscitating every patient who suffers an arrest. Confusion as to criteria for decisions not to resuscitate, identity of decision makers, and a proper decision making process has further obscured an already difficult problem. This instruction is intended to simplify the problem by establishing a clearly delineated decision making process, identifying the appropriate decision makers and providing both criteria for making such decisions and a system of review.

3. Policy. The overriding policy of this hopsital is to maintain life and health, and the autonomy of both patients and medical department personnel.

4. Procedures for Writing Orders Not to Resuscitate. The following elements must be contained in every instance of writing orders not to resuscitate (DNR orders). (Terms are defined in paragraph 8.)

* Guidelines for orders not to resuscitate NHBETH INSTRUCTION 6320.37, National Naval Medical Center, Bethesda, Md. 20814 (Feb. 9, 1983).

a. Only credentialled physicians may write orders not to resuscitate.

b. Orders must be clearly written, signed, dated and immediately shown to the ward or unit charge nurse.

c. The order not to resuscitate must be accompanied by a progress note describing the application of the decision making process. (See Tables 2 and 3.) [drawn from earlier drafts of the Commission's Report; see Tables 2 and 3, pp. 244, 247 *supra*]. The description will include:

(1) A statement indicating: *condition* (reversability/irreversability), *physical status* (reparability/irreparability), *mental status* (competent/incompetent/diminished competence), and *prognosis* (death imminent/nonimminent).

(2) Patient and family involvement including their attitudes and responses.

(3) Optimal care treatment plan.

d. The physician's discussion with the patient or family shall be witnessed by a registered professional nurse, or social worker, who will countersign the doctor's progress note.

e. DNR orders must be reviewed daily by the ward medical officer.

f. A staff physician must countersign all DNR orders and progress notes within twelve hours of their writing.

g. The Quality Assurance/Risk Management officer must be notified of the DNR order by the physician writing the order within twelve hours of writing the order. The QA/RM officer will then notify the Chairman of the Medical Ethics Committee of the order.

5. Questions or Disagreement. The patient, any member of the family or of the health care provider team who questions or disagrees with the writing of the DNR order, or the absence of a DNR order, should express that disagreement in writing to the medical ethics committee.

6. Medical Ethics Committee. The committee will act as a decision making and review committee on matters relating to DNR orders, as well as other matters at the direction of the Commanding Officer.

a. Composition. The committee will be composed of the following seven members:

One Medical Officer
One Chaplain Corps Officer
One Judge Advocate General Corps Officer
One Medical Service Corps Officer (administrative)
One Nurse Corps Officer
One psychiatrist or psychologist
One senior member of the Hospital Corps Staff

b. Action and Decision.

(1) The committee will review monthly all DNR orders. It will act immediately, however, in those cases where immediate action is warranted or requested.

7. Discussion.

a. Paramount Role of the Patient. Underlying guidance on DNR orders the time the question of resuscitation arises. There are two is the fundamental principle that the patient's desires play the dominant role in the decision process; however, patients may not be competent at dimensions to competence: factual and legal. The dimensions can be classified on a two by two matrix.

b. Legally and Factually Competent Patient. In general, when the competent patient requests a DNR order, the request will be honored, as outlined by Table 2 [drawn from the Commission's Report, *see* Table 2, p. 244 *supra*] regardless of the expected benefits of resuscitation.

The following cases will be given immediate attention by the committee:

(1) Third Party Interests. If reasons exist not to honor the patient's request for a DNR order (e.g., the patient is pregnant, is a sole or primary provider, and so forth), the case shall be referred to the committee. If the committee agrees there is a third party interest but the patient persists in his decision, the case will be referred to the courts. If the committee concludes that there is no third party interest, then the committee will consult with the individual asserting the third party interest. If this person then agrees with the committee, the patient's wishes are followed; if not, the case may be referred to the courts.

(2) Disagreement with Patient. In the event of diagreement with the patient by any health care provider or family member, the case will be referred to the committee. If the committee concurs with the individual in disagreement with the patient, the committee will recommend that a coercive offer (i.e., that the patient be transferred to another facility) be made or will refer the case to the courts. If the committee agrees with the patient, it will meet with the disagreeing person. If the health care provider does not agree, he shall comply with the committee's decision or be removed from the case. If the family continues in disagreement, it may refer the case to the courts.

(3) Military Personnel. Governmental claims of a right to require medical care for the individual member obtain only when it can reasonably be expected that the member can be returned to duty as an active and contributing member of the armed forces. Governmental rights should not, therefore, be considered in the case of the terminally ill patient or in the patient in which treatment could constitute undue suffering. In such cases, the patient is to be treated as a legally and factually competent patient.

c. Legally Incompetent, Factually Competent Patient.

(1) Minors. The decision not to resuscitate a minor must be made by the parent or a person standing in place of the parent. In making the decision, the parent or substitute must act in the best interest of the minor. In addition, in the case of a mature minor, the minor's assent should be obtained.

d. Incompetent Patient. Subsumed under the category of the incompetent patient is the patient with diminished competence. In all decisions the underlying principle is to attempt to determine the decision the patient would have made were he fully competent and informed. This is especially true in the case of the patient whose capacity is diminished as a consequence of pain, therapeutic regimen, or other factors associated with the illness.

(1) Table 3 [drawn from an earlier draft of the Commission's Report, see Table 3, p. 247 *supra*] summarizes the decision alternatives first as a function of the provider's assessment of benefit vis à vis the family's views and second as a function of the provider's recommendation and the family's views.

(2) All cases involving incompetence or diminished competence will be routinely reviewed by the committee. Before the DNR order is written, however, the case must be reviewed at least by a legal officer and psychologist or psychiatrist to establish competence. If the order is one that on Table 3 calls for review or reexamination, then the case must be reviewed by the committee before the order is written.

(3) When the committee concurs with the physician, members of the committee may assist the physician in clarifying the provider's assessment for the family. If the family remains unpersuaded, the provider may make a coercive offer or refer the matter to the courts.

(4) When the committee concurs with the family, it shall confer with the physician. If the disagreement remains, the physician shall comply with the committee's decision or be removed from the case.

8. Definitions. In general, the definitions contained herein are either consistent with or derived from the President's Commission for the Study of Ethical Problems in Medicine, and where applicable, local laws and military regulations.

a. Assent. The passive acceptance of a decision made by others.

b. Autonomy. The right of self determination, i.e., the right of competent persons to form, revise and pursue a plan of life. In matters of patient care and orders not to resuscitate, it means that the competent patient's own values shall be decisive. It also means that health care providers shall not be

required to act in a manner contrary to their own values or professional standards.

c. Competence. The ability to make an informed choice. In the case of orders not to resuscitate, it means that the patient understands the relevant risks and alternatives with their attendant consequences. The decision should reflect deliberate choice.

(1) Legal Incompetence. That situation in which an individual is incompetent by operation of law, e.g., a minor or a person previously declared incompetent by judicial decree. Under Maryland state law, a minor who is married or who is a parent is legally competent.

(2) Factual Incompetence. Those situations in which a patient is comatose, unconscious, suffering insane delusions or is otherwise unable to manage his or her personal affairs due to mental disability or disease.

d. Consent. Active participation in and agreement with a decision.

e. Death Imminent. That condition in which in the ordinary course of events, death will probably occur within two weeks. Note that while a death imminent prognosis is a contributing factor for an order not to resuscitate, its absence does not create a prohibition.

f. Diminished Competence. This condition exists when a patient cannot make decisions that promote his well being in accordance with his own previously expressed values and preferences. Diminished competence is often seen as a consequence of pain, therapeutic regimen, or other factor associated with the patient's illness.

g. Family. Those persons sharing a consanguineous relationship (blood) with the patient. In order of consanguinity, this includes the patient's spouse, children, parents and siblings.

h. Informed Consent. A principle of law embodied within the patient's autonomy or right of self determination. It requires that the patient must be informed of all proposed medical procedures, the material risks of those procedures, alternative courses of action and the material risks attendant to the alternatives.

i. Mature Minor. Those above the age of 14 will generally be considered mature minors. Those under the age of fourteen may be so considered at the discretion of the committee.

j. Optimal Care. Care which assures the comfort, dignity, and physical maintenance of the patient regardless of the existence of orders not to resuscitate.

k. Reparability. The extent to which the illness can be cured, corrected, or otherwise stemmed within existing knowledge and technology.

1. Reversability. The extent to which known therapeutic measures can effectively reverse the course of the illness.

m. Terminally Ill. That condition in which there is no reasonable medical possibility that the patient will avoid death and return to a normal cognitive and sapient state.

9. Action. Chiefs of directorates are required to ensure that the provisions of this instruction are understood and carried out. It is also highly recommended that those providers having to deal with orders not to resuscitate become familiar with the bibliography on the subject in the E. R. Stitt Library.

(signed)
J. J. Quinn

Statements from California State Government

Department of Health Services*

When considering the need for acute hospitalization, these five areas of care must be considered:

1. Physician Services

   Specific requirement for daily visits, *e.g.*, situations requiring physician skills to observe, evaluate and adjust orders.

2. Skilled Nursing Services

   Need for continuous availability of nurse for decision making and intermittent observation.

   Frequent skilled nursing services, treatment or procedures.

3. Medical Services Only Available in Acute Facility

   Surgical procedures usually performed in acute hospital operating room.

   Medical procedures usually performed in acute hospital.

   Diagnostic services that are complicated or prolonged if performed by outpatient department—Cases that make access to post-test bed rest and observation mandatory or cases which require special continued assistance by nurses or physician (*e.g.*, cardiac catheterization, carotid, lumbar and femoral arteriography; pneumoencephalography).

   Patients condition is fragile and complications would be likely to occur.

4. Rehabilitation Services

   Initial rehabilitation efforts.

   Rehabilitation requiring a multidisciplinary approach.

   Intensive therapy or rehabilitation requiring two or more sessions daily.

5. Psychiatric Services

   Patient requires a combination of two of the following:

   a. psychotherapy by the attending physician

   b. hospital drug management, *e.g.*, tricyclics, phenothiazines, or lithium

   c. shock therapy

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* *Level of Care Determination on Acute Care Patients, and How It Relates to a Terminal Patient With a " No Code" Status,* Field Instruction Notice 5-81, to Field Office Administrators, Medical Counsultants, and HCSNs from Stephen Harrison, Asst. Chief, Field Services Section (Feb. 6, 1981).

Patient requires services for the purpose of diagnostic study and/or services to reduce or control the patients psychotic symptoms necessitating hospitalization.

Environmental control for patients with acute psychiatric problem.

While the above is presented in general terms and is not meant to be either all inclusive, or mutually exclusive, it is used to show the major service areas and how they would relate to individual patients.

It should be noted that of the five (5) hospital service areas, only service area number two (2), Skilled Nursing Services, of and by itself *is not* justification for acute care hospitalization. Therefore, a terminally ill patient with a "no code" status and those care needs limited to making the person as comfortable as possible and free from pain, while preserving that person's personal dignity to the extent possible, would not meet the criteria for acute hospitalization.

It should be noted that some of the patients' skilled nursing care services may require the number of nursing hours or suppliers that will prevent a skilled nursing facility from accepting them. In these cases we should endeavor to have the patient admitted to a distinct part of an acute care hospital (SNF/DP) as an SNF patient. Should this not be possible, we should authorize the patient to be admitted to the acute hospital level and give the hospital realistic instructions regarding continued SNF placement efforts.

Attorney General's Office*

A California superior court lacks jurisdiction to order or approve the withholding or withdrawal of extraordinary life support systems or procedures from a person made a ward or conservatee pursuant to the Probate Code.

Requested by: COUNTY COUNSEL CONTRA COSTA COUNTY

Opinion by: GEORGE DEUKMEJIAN, Attorney General
Jack R. Winkler, Assistant

The Honorable John B. Clausen, County Counsel of Contra Costa County, has requested an opinion on the following question:

Does the Probate Court in California have the jurisdiction and power to order or approve the withholding or withdrawal

* Opinion on Jurisdiction to Order Withdrawal of Extraordinary Life Support Systems from Ward or Conservatee, Opinion No. 81-508 (July 2, 1982).

of extraordinary life support systems or procedures from a ward or conservatee?

CONCLUSION

A California superior court lacks jurisdiction to order or approve the withholding or withdrawal of extraordinary life support systems or procedures from a person made a ward or conservatee pursuant to the Probate Code.

ANALYSIS

Some definition of the terms used in the question is needed to focus upon the legal issues involved. The question concerns the jurisdiction of the "probate court." Strictly speaking there is no probate court as such in California. (Schlyen v. Schlyen (1954) 43 Cal. 2d 361, 371.) Article VI, section 10 of the California Constitution places the "original jurisdiction in all causes" except those given by law to municipal and justice courts in the superior court. Probate matters are civil cases and proceedings within the original jurisdiction of the superior court. (Schlyen v. Schlyen, supra.) Thus we understand the question to refer to the superior court exercising its original jurisdiction in probate matters and specifically to guardianship and conservatorship proceedings. (See Probate Code, § 2200.)[1]

The words "jurisdiction and power" in the question need some clarification. The term "jurisdiction" has so many meaning that no single statement can be entirely satisfactory as a definition. (Abelleira v. District Court of Appeal (1941) 17 Cal. 2d 280, 287.) Lack of jurisdiction in its most fundamental or strict sense means an entire absence of power to hear or determine the case, an absence of authority over the subject matter or the parties. (*Id.*, p. 288.) As we have noted the constitution gives the superior court jurisdiction over all probate matters in this fundamental sense. The court's fundamental probate jurisdiction in guardianship matters is a continuing one which is not concluded until the guardian is discharged. (Guardianship of Reynolds (1943) 60 Cal. App. 2d 669, 677.) The word jurisdiction is sometimes used to mean "simply authority over the subject matter or question presented," the "authority to do the particular thing done, or putting it conversely, a want of jurisdiction frequently means a want of authority to exercise in a particular manner a power whih the board or tribunal has, the doing of something in excess of the authority possessed." (Abelleira v. District Court of Appeal, supra, at 290.) Since the "probate court" undoubtedly has fundamental jurisdiction over the guardian appointed by it and the ward we understand the words "jurisdiction and power" in the question to refer to the court's jurisdiction in the sense of

[1] Section references are to the Probate Code unless otherwise indicated.

its authority to make the particular order referred to in the question. It is in this latter sense that we use the word "jurisdiction" in this opinion.

The question concerns the extent of the court's jurisdiction over a "ward or conservatee." California statutes create more than one kind of guardianship and conservatorship. Division 4 of the Probate Code governs the guardianship of minors generally and the conservatorship of the person and estate of incompetent adults generally. The Juvenile Court Law governs wards of the Juvenile Court. (Welf. & Inst. Code, § 601 et seq.) Under the Lanterman-Petris-Short Act a person committed to a state mental institution who is gravely disabled is subject to conservatorship proceedings under that law. (Welf. & Inst. Code, § 5350 et seq.) Since the question is concerned only with the court's probate jurisdiction we are here concerned only with those guardianships and conservatorships created pursuant to division 4 of the Probate Code. The question further limits the analysis to guardianships and conservatorships of the person as distinguished from those created solely to safeguard the estate of the ward or conservatee.

The question concerns "extraordinary life support systems or procedures." We understand life support systems or procedures to refer to those measures applied to a person's body which sustain some bodily function artificially and without which the person would be expected to die.[2] We further understand the word "extraordinary" to distinguish those systems or procedures which are utilized on a continuing basis as necessary to the person's health. Thus we are not here concerned with those treatment measures employed to replace or assist a vital function on a continuing basis such as a heart transplant, a pacemaker, kidney dialysis and the like. On the other hand we understand the systems and procedures referred to to be limited to those of a medical nature.

We understand the thrust of the question to be limited to those situations where the anticipated result of the withholding or withdrawal of extraordinary life support systems or procedures is the death of the ward or conservatee. Thus we do not

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[2] Compare Health and Safety Code section 7187(c) in the Natural Death Act which reads:

> "(c) 'Life-sustaining procedure' means any medical procedure or intervention which utilizes mechanical or other artificial means to sustain, restore, or supplant a vital function, which, when applied to a qualified patient, would serve only to artificially prolong the moment of death and where, in the judgment of the attending physician death is imminent whether or not such procedures are utilized. 'Life-sustaining procedure' shall not include the administration of medication or the performance of any medical procedure deemed necessary to alleviate pain."

consider in this opinion those situations where withholding or withdrawal of extraordinary life support systems or procedures is done for the purpose of sustaining or improving the medical condition of the ward or conservatee.

A person of adult years and in sound mind has the right, in the exercise of control over his own body, to determine whether or not to submit to lawful medical treatment. (Cobbs v. Grant (1972) 8 Cal. 3d 229, 242.) Thus in most cases the decision whether to undertake treatment is vested in the party most directly affected: the patient. (Cobbs v. Grant, supra, at 244.) Some authorities indicate that this right is included within the constitutionally protected right of privacy (see 58 Ops. Cal. Atty. Gen. 849 (1975)) but this is questionable since People v. Privitera (1979) 23 Cal. 3d 697 held that the constitutional right to privacy does not include medical treatment in a decision denying a person's right to take laetrile as a cure for cancer.

As new medical techniques have developed which artificially prolong vital body functions the decisions to employ them become more complex in particular situations. Even our traditional notions of life and death require more precise definition. When a person's circulation is maintained by a heart-lung machine and the person's brain has ceased functioning, can we say the person is still alive? When the patient is unable to decide whether such extraordinary life support measures are to be taken, who is to make such an awesome decision on his behalf?

As the questions have become more complex the laws governing their resolution have also become more complex. In 1974 Health and Safety Code section 7180 was enacted defining death as including total and irreversible cessation of brain function in addition to the customary procedures for determining death. In 1976 the Natural Death Act (Health & Saf. Code, § 7185 et. seq.) was enacted declaring an adult's fundamental right to control the decisions regarding his or her own medical care and establishing procedures to implement a decision that measures to artificially prolong life not to be taken in specified circumstances.

In 58 Ops. Cal. Atty. Gen. 849 (1975) we concluded that a conservator appointed under the Lanterman-Petris-Short Act had no authority to consent to medical treatment on behalf of the conservatee unless the conservatee was unable to give informed consent by reason of incompetence. Chapter 905, Statutes of 1976, amended Welfare and Institutions Code sections 5357, 5358 and 5358.2 in the Lanterman-Petris-Short Act to authorize a conservator appointed under that act to consent to medical treatment of a gravely disabled conservatee but requiring the conservatee's consent to any nonemergency surgery in the absence of a court order specifically authorizing such surgery. In 60 Ops. Cal. Atty. Gen. 375 (1977) we indicated

our view that guardians and conservators appointed pursuant to the Probate Code may not have a like authority to consent to medical treatment and suggested that they obtain court authorization for any medical decisions respecting their wards and conservatees until the law was clarified.

The extent of the authority of the court to authorize medical treatment of wards and conservatees was similarly uncertain. In Guardianship of Kemp (1974) 43 Cal. App. 3d 758 the father of an adult daughter who was capable of sex but mentally unable to understand its consequences was appointed the guardian of her person and estate. Doctors advised the father that the ward's pregnancy would probably result in her reconfinement in a state hospital, that other birth control measures were contraindicated and that her mental deficiencies might be transmitted to any child born to her. The father sought court approval to consent to the sterilization of his daughter. The superior court made an order authorizing the guardian to consent to the sterilization finding authority for its order "in the exercise of its residual chancery powers under the provisions of California Probate Code section 1400."[3] On appeal the court stated the issue thus:

> "Assuming that under the reasoning of the Reynolds[4] case, the probate court in the exercise of its continuing jurisdiction over a guardianship has authority by virtue of Probate Code section 1400 to issue instructions providing for the mental and physical welfare of an incompetent person, it must be determined whether a judgment of a probate court ordering a sterilization operation to be performed upon the person of an incompetent is within the limits of such jurisdiction."

The court noted that the only statute authorizing sterilization of a mentally incompetent person was Welfare and Institutions Code section 7254 which authorized sterilization of those committed to state mental hospitals under specified conditions. After reviewing California and out of state cases the court found no persuasive authority that a probate court had jurisdiction to authorize sterilization of a ward in the absence of a statute. The court reversed the superior court order

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[3] Probate Code section 1400 then provided:

> "A guardian is a person appointed to take care of the person or property of another. The latter is called the ward of the guardian. The relation of guardian and ward is confidential, and is subject to the provisions of law relating to trusts. In the management and disposition of the person or property committed to him, a guardian may be regulated and controlled by the court."

[4] Guardianship of Reynolds (1943) 60 Cal. App. 2d 669.

authorizing the guardian to consent to the sterilization holding that the order was in excess of the court's jurisdiction.

In Guardianship of Tulley (1978) 83 Cal. App. 3d 698 the court affirmed an order denying authorization for sterilization of a ward following the Kemp decision. The court in Tulley observed (at p. 701):

> "To begin with, it has been widely recognized that sterilization (even if medically and socially indicated) is an extreme remedy which irreversibly denies a human being the fundamental right to bear and beget a child. Accordingly, the overwhelming majority of courts hold that the jursidiction to exercise such awesome power may not be inferred from the general principles of common law, but rather must derive from specific legislative authorization. The position of case law is thus clear that in the absence of specific statutory authority the courts may not order the sterilization of a mentally defective person. (Citations.)"

If the courts lack jurisdiction to authorize the sterilization of a ward in the absence of statutory authority, their jurisdiction to order or approve the withholding or withdrawal of extraordinary life support systems or procedures upon which the life of the ward or conservatee depends must also be doubtful in the absence of specific statutory authorization. We conclude that a superior court's jurisdiction to order or approve the withholding or withdrawal of extraordinary life support systems or procedures from wards or conservatees may not be found in common law principles but must be derived, if it exists, from specific statutory authorization. (Guardianship of Tulley, supra, and Guardianship of Kemp, supra.)

Chapter 726, Statutes of 1979 (operative Jan. 1, 1981) provided clarification and statutory authorization for the medical treatment of wards and conservatees. It rewrote the whole of division 4 of the Probate Code relating to guardianships and conservatorships. Proceedings concerning unmarried minors are termed "guardianships" while those concerning married minors and adults are called "conservatorships." (See §§ 1485, 1490.) Part 4 of division 4 concerns provisions common to guardianships and conservatorships and chapter 5 of part 4 defines the powers and duties of the guardian or conservator of the person. The provisions concerning medical treatment of wards and conservatees are sections 2252, 2353, 2354, 2355, 2356 and 2357. These sections are set forth in full in the Appendix. Under section 2353(a) the guardian of a minor has the same right as a parent having legal custody of a child to give consent to medical treatment of the ward. The parent's rights are defined in Civil Code section 25.8 which reads:

> "Either parent if both parents have legal custody, or the parent or person having legal custody or the legal

guardian, of a minor may authorize in writing any adult person into whose care the minor has been entrusted to consent to any X-ray examination, anesthetic, medical or surgical diagnosis or treatment and hospital care to be rendered to the minor under the general or special supervision and upon the advice of a physician and surgeon licensed under the provisions of the Medical Practice Act or to consent to an X-ray examination, anesthetic, dental or surgical diagnosis or treatment and hospital care to be rendered to the minor by a dentist licensed under the provisions of the Dental Practice Act."

These new statutes provide a comprehensive legislative scheme to determine who is to authorize medical treatment for wards and conservatees. The guardian of a ward is given the same authority as a parent to consent to medical treatment of his minor child. (§ 2353.) The only exception is surgery for a ward 14 years of age or older in which case the consent of the ward as well as the guardian is required. The right to consent to medical treatment is not taken from a person who is made a conservatee unless it has been expressly found and adjudicated that he lacks the capacity to make an informed consent therefor, though the conservator may consent to medical treatment for the conservatee in emergencies. (§ 2354.) Where the conservatee has been adjudicated to lack the capacity to make an informed consent to medical treatment, the conservator is authorized to provide such consent. (§ 2355(a).) A temporary guardian or conservator has the same powers as a permanent representative under sections 2353 and 2354 (not under § 2355) unless the court orders otherwise. (§ 2252.) Section 2357 authorizes the court to authorize medical treatment for wards and conservatees under specified circumstances. Our research has revealed no case construing these new statutes. Accordingly, we must resort to the applicable rules of statutory construction which were summarized in Moyer v. Workmen's Comp. Appeals Bd. (1973) 10 Cal. 3d 222, 230, as follows:

"We begin with the fundamental rule that a court should ascertain the intent of the Legislature so as to effecutate the purpose of the law. In determining such intent the court turns first to the words themselves for the answer. We are required to give effect to statutes according to the usual, ordinary import of the language employed in framing them. If possible, significance should be given to every word, phrase, sentence and part of an act in pursuance of the legislative purpose; a construction making some words surplusage is to be avoided. When used in a statute words must be construed in context, keeping in mind the nature and obvious purpose of the statute where they appear. Moreover, the various parts of a statutory enactment must be harmonized by considering the particular

clause or section in the context of the statutory framework as a whole." (Citations and quotations omitted.) Section 2357(b) provides:

"If the ward or conservatee requires medical treatment for an existing or continuing medical treatment which is not authorized to be performed upon the ward or conservatee under section 2252, 2353, 2354 or 2355, and the ward or conservatee is unable to give an informed consent to such medical treatment, the guardian or conservator may petition the court under this section for an order authorizing such medical treatment and authorizing the guardian or conservator to consent on behalf of the ward or conservatee to such medical treatment."

Section 2252 gives a temporary guardian or conservator the powers specified in sections 2353 and 2354 unless the court orders otherwise. Section 2353(b) provides that surgery may not be performed on a ward 14 years of age or older without the consent of both the ward and the guardian or "a court order obtained pursuant to section 2357 specifically authorizing such treatment." Section 2354(b) provides:

"The conservator may require the conservatee [who has not been adjudicated to lack the capacity to give informed consent for medical treatment] to receive medical treatment whether or not the conservatee consents to such treatment, if a court order specifically authorizing such medical treatment has been obtained pursuant to section 2357." Section 2355(b) limits the authority of a conservator of a conservatee adjudicated to lack the capacity to give informed consent to medical treatment and was an adherent of a religion whose tenets and practices call for reliance on prayer alone for healing before the conservatorship was established to consent to treatment of such conservatee only by an accredited practitioner of that religion. The Law Revision Commission Comment to section 2355 notes that subdivision (b) "does not limit the authority of the court under Section 2357." Interpretive comments by the California Law Revision Commission are viewed as particularly well-accepted sources from which to ascertain legislative intent. (Davis v. Cordova Recreation & Park Dist. (1972) 24 Cal. App. 3d 789, 796.) In the foregoing situations the guardian or conservator may petition the court for an order authorizing medical treatment of the ward or conservatee if the ward or conservatee is unable to give an informed consent therefor.

Section 2357(i) provides in part:

> "Upon petition of the ward or conservatee or other interested person, the court may order that the guardian or conservator obtain or consent to, or obtain and consent to, specified medical treatment to be performed upon the ward or conservatee..."

The Law Revision Commission Comment to section 2357 states:

> "This subdivision covers the situation where the ward or conservatee or some interested person believes the ward or conservatee needs medical treatment which the guardian or conservator is unwilling to obtain or has failed to obtain."

Except for special notice requirements specified in the last sentence of subdivision (i) we believe the Legislature intended the same procedural requirements for court orders authorizing medical treatment of wards or conservatees upon the petition of the ward, conservatee or other interested persons under subdivision (i) as those sought by petition of the guardian or conservator under subdivision (b), namely those required by section 2357.

A procedural requirement of particular significance on the question presented is section 2357(h) which provides:

> "(h) The court may make an order authorizing the recommended course of medical treatment of the ward or conservatee and authorizing the guardian or conservator to consent on behalf of the ward or conservatee to the recommended course of medical treatment for the ward or conservatee if the court determines from the evidence all of the following:
>
> "(1) The existing or continuing medical condition of the ward or conservatee requires the recommended course of medical treatment.
>
> "(2) If untreated, there is a probability that the condition will become life-endangering or result in a serious threat to the physical health of the ward or conservatee.
>
> "(3) The ward or conservatee is unable to give an informed consent to the recommended course of treatment."

We note first that the courts' authority under section 2357(h) is to "make an order authorizing the recommended course of medical treatment of the ward or conservatee." What is the "recommended course of medical treatment"? Section 2357(c) provides that the petition shall state or set forth by medical affidavit:

> "(1) The nature of the medical condition of the ward or conservatee which requires treatment.
>
> "(2) The recommended course of medical treatment which is considered to be medically appropriate.
>
> "(3) The threat to the health of the ward or conservatee if authorization to consent to the recommended course of treatment is delayed or denied by the court.
>
> "(4) The predictable or probable outcome of the recommended course of treatment.

"(5) The medically available alternatives, if any, to the course of treatment recommended.

"(6) The effort made to obtain an informed consent from the ward or conservatee."

The information required, at least as to the first five items, would appear to be matters within the special knowledge of the doctor or doctors in charge of the medical treatment of the ward or conservatee. We think it is the recommendation of those medical practitioners which the Legislature had in mind when it required the petition to state "The recommended course of medical treatment which is considered to be medically appropriate." It is that statement and the evidence which supports it that constitutes the "recommended course of medical treatment" which the court may authorize under section 2357(h).

Next we note that section 2357(h) requires that the court must make three findings before it may make an order authorizing the recommended course of medical treatment, namely:

"(1) The existing or continuing medical condition of the ward or conservatee requires the recommended course of medical treatment.

"(2) If untreated, there is a probability that the condition will become life-endangering or result in a serious threat to the physical health of the ward or conservatee.

"(3) The ward or conservatee is unable to give an informed consent to the recommended course of treatment."

We noted previously our understanding that the question was directed at those situations in which the anticipated result of the withholding or withdrawal of extraordinary life support systems or procedures is the death of the ward or conservatee. Neither of the findings required by paragraphs (1) or (2) of section 2357(h) could be made in such situations. Accordingly, we conclude that a California superior court lacks the jurisdiction to order or approve the withholding or withdrawing of extraordinary life support systems or procedures from a person made a ward or conservatee pursuant to the Probate Code.

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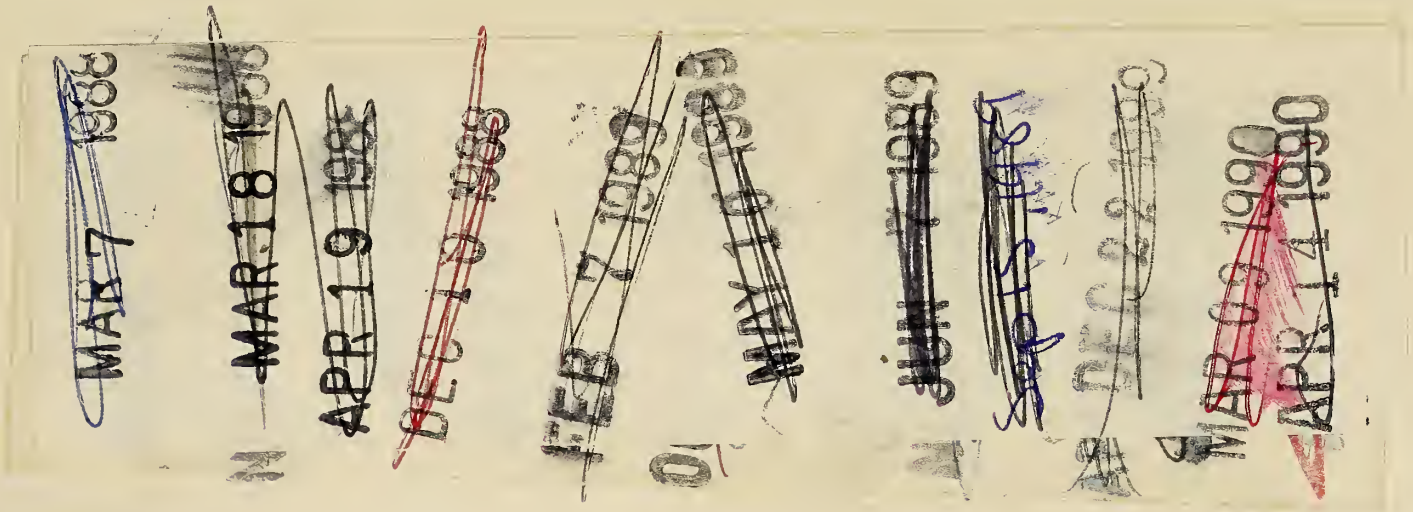

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